

Mothers' lived experiences of caring for their child with HIV-related neurodevelopmental disorder/s



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ABSTRACT

Although various measures, such as the Prevention of Mother to Child Transmission (PMTCT) programme, have been put in place to combat the spread of HIV/AIDS, there are still many cases of children, in Zimbabwe, being born infected with HIV. Children born to HIV parents are reported to be at risk of having neurodevelopmental disorders (NDDs), which can reduce independence in activities of daily living by imposing varying limitations on these children. Technological advances in the field of HIV/AIDS have resulted in prolonged life for people infected with HIV/AIDS and therefore there is a growing population of mothers caring for their biological children who are infected with HIV. The aim of this study is focused on exploring the experiences of being a mother and caring for a child with HIV-related NDDs in Zimbabwe. Specific objectives were to describe the mothers' experiences of engaging in the daily occupations of caring for a child with NDDs; to explore and describe factors that the mothers' perceived to impact on their experiences while caring for their children and how these experiences of caring shape the mothers' own occupational identities and engagement. A descriptive phenomenological approach was designed to uncover their lived experiences of caring for a child with HIV-related NDDs. In-depth data was generated from phenomenological interviews conducted with five biological mothers who have been caring for their own children who have been diagnosed with HIV-related NDDs. A thematic analysis, guided by a simplified version of the Stevick-Colaizz-Keen method, was employed. The findings revealed the transactional nature of the mothers' experiences of the occupation of caring for a child with HIV-related NDD. Personal factors interacted with contextual factors such as stigma, culture and socioeconomics to shape their caring experiences, making caring for their child, a difficult and demanding role that they could not easily entrust to another. Although the mothers voiced that this caring was comprised of many burdensome tasks, the mothers reframed the concept of the caregiver burden because they placed high value on and drew meaning from being a good mother to their child, thus making it an occupation that they would not readily entrust to another. The findings of this study encourage occupational therapists to consider carefully the resilience of these mothers and how their role as carers positively shapes their identities in the design of interventions for the mothers.

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DEDICATION

I dedicate this work to all the mothers in the world.

CONTENTS

Declaration.....	ii
Abstract.....	iii
Acknowledgements.....	iv
Dedication.....	v
Contents.....	vi
List of Appendices in English.....	ix
List of Appendices in Shona.....	x
List of Figures.....	x
List of Tables.....	x
Operational Definitions and Terminology.....	xi
Abbreviations, Acronyms and Definitions.....	xiii
Chapter 1. Introduction.....	1
1.1 Background.....	1
1.1.1 Caring in the context of HIV/AIDS.....	2
1.1.2 Caregiving of mothers and occupational therapy.....	3
1.1.3 Caregiving in the Zimbabwean Context.....	4
1.2 Personal Stance.....	5
1.3 Problem Statement.....	6
1.4 Rationale.....	6
1.5 Purpose of Study.....	7
1.6 Research question.....	8
1.7 Research Aim.....	8
1.8 Specific objectives of the study were as follows:.....	8
1.9 Outline of the research.....	8
1.10 Conclusion.....	9
Chapter 2. Literature Review.....	10
2.1 Introduction.....	10
2.2 Caregiving and Caring framed as occupations of mothers.....	10
2.3 The occupation of caring by mothers of children who are chronically ill and / or disabled.....	11
2.4 Contextual factors that shape the caregiving occupation of mothers of children with HIV NDD.....	16

2.5 Occupational Therapy Interventions for caregivers of children with chronic illness and disability.....	19
2.6 Conclusion.....	21
Chapter 3. Methodology.....	22
3.1 Introduction.....	22
3.2 Research design.....	22
3.3 Research Setting.....	23
3.4 Participants selection.....	24
3.4.1 Inclusion Criteria	24
3.4.2 Exclusion Criteria	25
3.4.3 Sample size	25
3.4.4 Procedure of Sampling.....	25
3.4.5 The Participants	26
3.5 Data collection Schedule.....	28
3.5.1 Data collection methods.....	29
3.5.2 Pilot Interview.....	30
3.5.3 Procedure of data collection.....	31
3.5.4 Data storing methods	32
3.5.5 Data Analysis Procedure.....	33
3.6 Data report and discussion	36
3.7 Scientific Rigour or Trustworthiness of the study	36
3.7.1 Credibility	36
3.7.2 Confirmability.....	37
3.7.3 Dependability.....	37
3.7.4 Transferability.....	38
3.8 Ethical considerations	38
3.8.1 Introduction.....	38
3.8.2 Autonomy	39
3.8.3 Confidentiality	39
3.8.4 Beneficence.....	40
3.8.5 Risks and Discomforts	40
Chapter 4. Findings.....	41
4.1 Introduction	41
4.2 Theme One: “Resilient Acceptance (Ndozvazviri)”	41
4.3 Theme Two: “Caring for My Child is too much to entrust to another”	46

4.4 Theme Three: “Rekindled hope for the future”	57
Chapter 5. Discussion	66
5.1 Introduction	66
5.2 Guilt, shame and self-blame fostering the complete investment of mothers in their role as caregivers	66
5.3 Contextual factors shaping caregiving experiences	68
5.4 A reconsidered view of caregiver burden	72
5.5 Power of Collectives	74
5.6 Conclusion.....	76
Chapter 6. Recommendations and Limitations.....	77
6.1. Recommendations	77
6.1.1 Recommendations to occupational science	77
6.1.2. Recommendations to occupational therapy practice.....	77
6.1.3 Recommendations for further research	78
6.2 Limitations of the study.....	79
6.2.1 Sampling	79
6.2.2 Data Collection Method.....	80
6.3 Conclusion.....	80
References	i
Appendices	i
Appendix A: Literature Review Mapping	ii
Appendix B: Information Letter (English)	iii
Appendix C: Informed Consent (English).....	ix
Appendix D: Interview Protocol (English).....	xi
Appendix E: Second Line Interview Guide	xv
Appendix F: Approval from Harare Central Hospital	xvii
Appendix G: HREC Ethical Approval	xviii
Appendix H: Approval from Medical Research Council of Zimbabwe.....	xix
Appendix I: Significant Statements from Participants.....	xx

LIST OF APPENDICES IN ENGLISH

Appendix A:	Literature Review Mapping	ii
Appendix B:	Information Letter (English)	iii
Appendix C:	Informed Consent (English)	ix
Appendix D:	Interview Protocol (English)	xi
Appendix E:	Second line Interview Guide	xv
Appendix F:	Approval from Harare Central Hospital	xvii
Appendix G:	HREC Ethical Approval	xviii
Appendix H:	Approval from Medical Research Council of Zimbabwe	xix
Appendix I:	Significant Statements from Participants	xx

LIST OF APPENDICES IN SHONA

Appendix B 1:	Information Letter (Shona).....	vi
Appendix C 1:	Informed Consent (Shona).....	x
Appendix D 1:	Interview Protocol (Shona).....	xiii
Appendix E 1:	Second line interview guide (Shona).....	xvi

LIST OF FIGURES

Figure 3.1: Data Analysis Process	33
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LIST OF TABLES

Table 3-1: Demographics of Participant Mothers.....	28
Table 3-2. Data Collection Schedule	29
Table 4-1: Themes and sub-themes	41

OPERATIONAL DEFINITIONS AND TERMINOLOGY

Caring:

In this study, ‘caring’ is defined as the provision of assistance to a child (who is ill, disabled or needs help with daily activities) by his or her biological mother. In this study, the term ‘caring’ will be used synonymously with ‘caregiving’ and will be framed as an occupation of mothers.

Context:

In this study, ‘context’ refers to the physical, social, psychological and economic environment in which an individual resides.

Mothers:

The term, ‘mothers’ has been used to refer to biological mothers of children with HIV-related neurodevelopmental disorders (NDD) who were the participants of this study

Co-occupation:

‘Co-occupation’ is when two or more people share engagement in an occupation, in a mutually responsive and interconnected manner (Pickens & Pizur-Barnekow, 2009, p. 152).

HIV-related neurodevelopmental disorders:

These are disorders in children which occur as a result of the detrimental neurotropic effect of HIV on the developing brain. These disorders can cause learning difficulties, cerebral palsy, intellectual disabilities, delayed milestones; they have various subsequent impact on the independence of the children in the activities of daily living (Potterton, Cooper, Goldberg, Gajdosik & Baillieu, 2009).

Lived Experience:

Everyday experiences that one encounters which are understood in greater depth upon reflecting on the meanings a person or persons ascribes to these experiences (Van Mannen, 1997).

Occupation:

‘Occupation’ “...is defined as the ordinary things that people do every day and the way they spend their time, energy, interests and skills in meeting their needs.” (Townsend & Wilcock, 2004, p. 244).

Occupational Identity:

“A composite sense of who one is and wishes to become” evolving in relation to a person’s occupational participation over the course of their lives (Kielhofner, 2008, p. 119).

Resilience of a caregiver:

“A process of interaction between the caregiver and the environment and is a balance between protective factors and risk factors. When placed in an unbalanced stressful situation a caregiver proactively seeks balance in life appraising the positive meaning of the event.” (Lin, Rong & Lee, 2013; p. 328)

ABBREVIATIONS, ACRONYMS AND DEFINITIONS

AIDS:	Acquired Immune-Deficiency Syndrome
CRU:	Children's Rehabilitation Unit
<i>et al.</i>	(Latin) 'and others'
HREC	Faculty of Health Sciences Human Research Ethics Committee, University of Cape Town
HIV:	Human Immunodeficiency Virus
<i>Ibid</i>	(Latin) 'from the same source'
NDD:	Neuro Developmental Disorder/s
PMTCT:	Prevention of mother to child transmission
Ubuntu	The African cultural belief that each person is inextricably bound to the whole of humanity; what happens to one, affects the whole group
UNAIDS:	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

Chapter 1. INTRODUCTION

The chapter provides the background information to define this study's focus area – caregiving from mothers, living in Zimbabwe, for their children with HIV-related Neurodevelopmental Disorder/s (NDD). Furthermore, the chapter presents the aim, objectives, purpose and justification for the study.

1.1 Background

More than twenty years after it was first diagnosed, HIV remains a major global health problem, despite global solidarity in response to the epidemic (Demmer, 2011). According to the UNAIDS (2012) report, approximately 34 million people globally are living with HIV. Sub-Saharan Africa remains the most severely affected, with nearly one in every 20 adults (4 - 9%) living with HIV, accounting for 69% of the population of people living with HIV worldwide (UNAIDS, 2012). There are approximately one million children in sub-Saharan Africa infected with HIV. This figure accounts for 90% of the HIV-infected children in the world. Approximately 120 000 children are living with HIV/AIDS in Zimbabwe (UNAIDS, 2012).

Despite measures to mitigate HIV/AIDS in Zimbabwe, the HIV pandemic has increasingly affected children, resulting in the reversal of the gains made in the reduction of infant and childhood morbidity and mortality in the country (Kuonza, Tshuma, Shambira & Tshimanga, 2010). The most dominant mode of acquisition of HIV infection in children has been during pregnancy, delivery or breastfeeding (UNAIDS 2008). In the absence of HIV prevention measures 35% of children born to Zimbabwean mothers who are HIV-positive, will contract the virus. This places these Zimbabwean children at a 9.4% risk of developing NDD (Kandawasvika, Ogundipe, Gumbo, Kurewa, Mapingure & Stray-Pedersen, 2011).

Although the association between HIV-Infection and neurodevelopment in infants and children in resource-poor settings has not been well established (Doare, Bland & Newell, 2012), NDD is a well-known complication of the HIV disease (Van Rie, Mupuala & Dow, 2008). This risk is also supported by Potterton, Stewart, Cooper, Goldberg, Gajdosik and Baillieu, (2009a), who highlighted that neurological complications and resultant developmental delay are seen more

frequently in HIV-positive children. Potterton *et al.*'s (2009a) study of South African HIV-positive children under 24 months revealed that these children had indications of developmental delay in all areas of sensory-motor, cognitive and speech development because of impairment of the central nervous system.

NDD occurs when HIV-1 enters the central nervous system, days or weeks after the primary infection, causing neuronal damage and cell death (Doare *et al.*, 2012). Children with HIV-related NDD are likely to present varying signs and symptoms dependent on the stage at which the HIV infection occurred within the growing central nervous system. Clinical signs of HIV infection are neurodevelopmental delays which can be exhibited as delays in developmental milestones, cognitive delay and neuropsychological functioning (Potterton *et al.*, 2009a). Neurodevelopmental disorders can present as delay or loss of either motor, language or mental development (Van Rie *et al.*, 2008).

In summary, children infected with HIV are at risk of developing neurodevelopmental impairments, with cognitive, motor and emotional components (Stein, Krebs, Richter, Tomkins, Rochat & Bennish, 2005). Delays in development can result in learning difficulties, cerebral palsy and other disabilities which prohibit the child from participating optimally in their expected occupations (such as self-care, schooling and play). These children would depend more on the carer for daily activities when compared with the needs of other children (Nicholl & Begley 2012). Thus caring for a child with HIV-related neurodevelopmental disorder is a unique kind of parenting that encompasses many unusual childcare practices (Bourke-Taylor, Howie, & Law, 2010).

1.1.1 Caring in the context of HIV/AIDS

In the past it was common for most carers of HIV-infected children in Africa to be either grandmothers, siblings or extended family members because most biological mothers would have – died or would have been too seriously ill – as a result of the HIV/AIDS disease (Kuo & Operario, 2009). Recent advances in healthcare practices, linked to the advent of antiretroviral therapy, have increased the life expectancy and quality of life of HIV-infected people. There is now a growing population of HIV-positive mothers caring for their own children.

The diagnosis of a child to be HIV-positive almost always means that at least the mother (and possibly the father) is also infected (Potterton Stewart & Cooper, 2009b). Thus most children are born to mothers who will have episodes of ill health because of high HIV viral loads (Doare *et al.*, 2012). This makes caring for an HIV child, by a biological mother, different from caring during other chronic childhood diseases, because the mother has to deal with her own diagnosis and the possibility that both the child and any partner/s have the disease as well (Potterton *et al.*, 2009b). Many mothers only learn about their HIV status at the same time that they find out that they are pregnant. They have to deal with feelings of shock, anxiety, fear and guilt (D'Auria, Christian & Miles, 2006). The diagnosis of HIV/AIDS, couples with stigma and adds an additional layer to the burden of care, compelling mothers to deal with the tension between the preference for privacy (secrecy) surrounding the disease and the openness required for both providing proper care for their child and seeking and accepting social support (Van Graan, Van der Walt & Watson, 2007; Hejoaka, 2009).

In the African context, the cultural and societal norms of caregiving obligate the mother to care for and be responsible for her own child. Caring for one's own child gives mothers both a meaningful identity and a sense of belonging (Vallido, Wilkes, Carter & Jackson, 2010). Often HIV-positive mothers tend to silence their own needs and attend to the needs of their children (DeMarco, Lynch & Board, 2002). In most instances, the mothers ignore their physical, psychological and social needs and/or seek services and support late, thus, negatively impacting on their own general health and, consequently, the health of their child. These unique challenges, related to the caregiving experience, motivate the need for an inquiry into the lived experiences of mothers caring for their own children with HIV-related NDDs.

1.1.2 Caregiving of mothers and occupational therapy

Most occupational therapy clients have disabling conditions which make them dependent on the caregiver for day-to-day activities (Moghim, 2007). As occupational therapy practice regains its focus on enabling participation in occupations (Townsend, Stone, Angelucci, Howey, Johnson, & Lawlor, 2009), there is a need to consider all the varied factors and significant persons who may shape and influence participation. For occupational therapists working with children, this relates to the importance of focusing, not only on the occupations of the children but also on the occupations of their mothers. Mothers are key significant figures in the lives of their children. In most cases they are the primary caregivers and therefore the

persons most knowledgeable about the health and needs of the children (Montes & Halterman, 2007). Focusing on the occupation of mothers, as caregivers, is vital to good occupational therapy because mothers have the potential to either hamper or promote the successful rehabilitation of their children (Sungh, Chaudor, Escobar & Kalichman 2011).

Caregiving is an occupation reported to have both positive and negative effects on both the carer and the one being cared for (Green, 2007). Like other occupations, caregiving has the potential either to promote health and wellbeing or to be experienced as a form of injustice (Townsend & Wilcock, 2004). Informed by the theories of occupational science, occupational therapy plays a role in enabling engagement and participation in positive caregiving practice. Occupational therapists have a role to play in the caregivers lives – this is to promote knowledge and skills that address physical, psychosocial, cognitive, sensory and contextual factors that affect their patients' participation in everyday life activities (O'Sullivan, 2007).

However, Bourke-Taylor *et al.* (2010) states that nature of occupational therapy support to caregivers is not known. This might be because occupational therapy intervention and support is client specific; it varies from one individual or group to another. Occupational therapists use a client-centred approach which entails the involvement of clients in decision-making and empowerment (Hammell, 2010). This premise is also supported by Kuo (2011) who stated that more meaning in occupations can be found if the individual has been given the opportunity to both choose and act on them and also achieve pleasurable experiences. Thus the first need is to contextually understand the mother's caring experience for a child with HIV-related NDD, thereby formulating the effective support for mothers in their caring occupation.

1.1.3 Caregiving in the Zimbabwean Context

The primary health care approach adopted by the Ministry of Health and Child Care (Zimbabwe National Health Strategic Plan 2009-2013) has resulted in shorter hospital admission periods and patients are discharged to recover within their individual communities. The Plan further states that the current health system must rely heavily on informal caregivers (mostly the family) for the day-to-day care of people with chronic conditions. Home-care has become central for most chronic conditions – including HIV/Aids (Hejoaka, 2009; Sungh *et al.*, 2011). Caregiving is an occupation that is integral to the total management of the children: caregivers provide an on-going daily care for them (Sungh *et al.*, 2011)

Involvement of the mother in rehabilitation is important because the mother has a greater role to play in the development of child and spends more time with the child than the therapist (Moghim, 2007). In Zimbabwe, the researcher observed that rehabilitation for children has been structured in such a way that most children are seen as outpatients. The therapist assesses the child and provides the mother with a home programme; the mother effectively becomes an extension of the rehabilitation at home. Follow-up and support is given by the therapists in the form of outreach, support groups and reviews at the hospital. There was a general agreement among occupational therapists in Zimbabwe that incorporation of the carer in treatment was of immense benefit to the child's progress. This validates the need to understand the lived experience of caring for a child with HIV-related neurodevelopmental disorder in a Zimbabwean context.

1.2 Personal Stance

The researcher was employed for 5 years (2007-2011) at an outpatient rehabilitation clinic within the Parirenyatwa Group of Hospitals in Harare, Zimbabwe. The outpatient department held fortnightly cerebral palsy clinics on Tuesdays. Children with HIV/AIDS-related NDDs were mostly referred and could attend this clinic fortnightly. The clinic was not only meant for cerebral palsy clients but also for children who had delayed milestones, spinal bifida, microcephaly, autism, hearing and speech disorders together with other paediatric conditions.

Treatment by an occupational therapist in the cerebral palsy clinic was for 45 minutes to one hour long. Because of the limited number of times the mother is able to visit the clinic, and the high volume of patients, the occupational therapist assesses the child and demonstrates what the mother has to do at home. In other words, the mother was empowered to continue with therapy at home, additional to the other roles: as a mother, caregiver, breadwinner and community member. The researcher has noticed and experienced the limitations inherent in providing effective home programmes without a deeper understanding of the mothers' lives. It has been within this context that the researcher developed an interest in understanding the mothers' lived experience of caring for a child with HIV-related NDD, primarily so better support strategies and more effective interventions could be formulated.

1.3 Problem Statement

The health and wellbeing of children is inextricably linked to the physical, emotional and social health of their caregivers (Potterton *et al.*, 2009b). Thus, there is need for occupational therapy practices to incorporate not only the concerns of the child but also the concerns of the mothers. This is even more critical for mothers of children with HIV-related NDDs, who, the researcher discovered, had other issues to deal with – issues which complicated their role as carer for their child. HIV stigma, poverty and lack of psychosocial support are among the issues that the mothers have to deal with, quite apart from their caregiving roles. Hocking (2009) stated that enhanced knowledge of occupations will make therapists better equipped to use occupation therapeutically because this insight would allow them to better understand their clients. Without an understanding of the caregiving occupation, occupational therapists will have difficulty incorporating activities into their practice that will positively affect the health and wellbeing of both the child and the caregiver (Moghimini, 2007). The difficulty is exacerbated by the paucity of literature on the caring occupation for children with NDD, especially in Zimbabwe. Hence the need to gain a better understanding of the experience of caring for a child with NDD, particularly to inform occupational therapy practice to be more responsive to the occupational needs of both the mother and the child.

1.4 Rationale

In Zimbabwe approximately 620 000 women, aged 15 to 64, are living with HIV, and approximately 42 000 (51.7%) HIV-positive pregnant woman are receiving antiretroviral therapy (UNAIDS, 2012). The programme for the prevention of mother-to-child transmission (PMTCT) of HIV was initiated in Zimbabwe in 1999. However, its availability and use in public clinics is limited (Orne-Glieman, Mukotekwa, Perez, Miller, Sakarovitch, Glenshaw, Engelsmann, & Dabis, 2006; Kuonza *et al.*, 2010). Hence the need for more studies on issues facing the population of HIV-infected mothers – especially if prevention, promotion of quality of life and eradication of HIV/AIDs are to be achieved.

The burden of both caregiving in HIV/AIDS and the link of HIV/AIDS with disability have been explored (Green, 2007). However, the effects of changes in occupation that result from caregiving responsibilities, and the impact of HIV on caregiving occupation, has not been researched (Ludwig, Huttgar, Russell & Winston, 2007). Moreover, in Zimbabwe, there is little

or no literature on caregiving occupations available, especially in the face of HIV. Case-Smith (2009), in her editorial message, pointed out that occupational therapy practices that support caregivers are hidden elements of the therapists' role; they are embedded in the treatment interactions with family and are neither well-defined nor well-researched.

Caregivers' occupational needs and role demands have to be incorporated into occupational therapy therapeutic interventions (Moghimi, 2007). One way to achieve this is through an in-depth understanding of the lived experiences of mothers of children with neurodevelopmental disorders. Understanding and empathising with the meanings they draw from their lived experiences of caring for a child with HIV-related NDD can be important tools for developing pleasurable experiences, giving the therapist the opportunity to examine how their meanings drive their participation and, in turn, influences their wellbeing (Larson, 2009). Therefore it is key for the occupational therapists to engage in research that will allow them to transform their practices and generate and enhance their approaches to the newly emerging clientele group of biological mothers providing care for children with HIV-related neurological disorders.

1.5 Purpose of Study

The purpose of this study is to gain an understanding of the caregiving occupation directly from the mothers who are caring for children with HIV-related NDDs. The data generated will add to the discipline of occupational science and the body of knowledge of the profession of occupational therapy, augmenting their understanding of the occupational demands for caring for children with HIV-related NDD. It is envisaged that the findings of this study would help guide occupational therapists how best to support mothers in their role of carers to their children.

Improving the health and quality of life, especially of women, is one of the objectives of the government of Zimbabwe – through the Ministry of Health and Child Care (National Health Strategic Plan (2009-2013)). To develop effective and efficient ways of improving health and quality of life for the mothers, there is a need to understand the everyday experiences of the mothers. Knowledge of the experiences of mothers caring for children with HIV-related NDD can be used at governmental levels to formulate policies and structures that would better support the mothers in Zimbabwe.

1.6 Research question

What is it like for mothers to care for children with HIV-related neurodevelopmental disorders?

1.7 Research Aim

The study is aimed at describing the lived experiences of mothers caring for children with HIV-related neurodevelopmental disorders.

1.8 Specific objectives of the study were as follows:

- To describe the mothers' experiences of engaging in daily occupations related to caring for their child/children with HIV-related NDDs;
- To explore and describe the factors that the mothers perceived to impact on their experience of caring for their child/children with HIV-related NDDs;
- To explore and describe the ways in which caring for the child with HIV-related NDDs shapes the mothers' own occupational identities and engagements.

1.9 Outline of the research

Chapter 1: provides the background of the study. First it highlights the impact of HIV/Aids and the resulting consequences of NDDs in children. It further explores caring in the context of HIV/Aids, in a Zimbabwean environment. The researcher also shares her personal experience as a therapist working with mothers of children with HIV-related NDD in Zimbabwe. The study strives to develop an understanding of what it is like to care for a child with NDDs from the biological mothers. The study will describe the experiences of engaging in daily occupations related to caring for a child with NDD, together with the factors that impact on the caring experiences, rewards and challenges experienced by the mothers.

Chapter 2: is a review of literature relevant to this study. The literature will be reviewed and presented in four sections. The first section endeavours to frame caregiving as an occupation. The second section reviews the burden of caregiving. The third section concentrates on caregiving in the context of HIV/Aids. Interventions for the caregiver are reviewed in the last section.

Chapter 3: will address the methodology of the study. It will discuss the sensitive nature of the various participants – who happen to be mothers of children with HIV-related NDD – were recruited and interviewed. An outline of how the data generated during the interviews has been analysed will also be given. The chapter further presents the ethical considerations and methods of increasing scientific rigour throughout the research process.

Chapter 4: presents the findings of this study. Data generated from the interviews with the mothers, coupled with reflections from both the mothers and the researcher, was analysed. Three themes emerged from the analysis and these will be discussed in this chapter under the following three topics: ‘Ndozvazviri’ (resigned acceptance); ‘Too much to entrust to another’; and ‘Rekindled hope for a future’.

Chapter 5: provides a discussion of the findings, drawing on insights from the transactional perspective of occupation, to highlighting the interplay of the context and personal factors shaping the caring experiences of the mothers. An extended view of the occupation of caring, focused on grasping the ‘meaning-making’ processes of the mothers in this study, is described. How they, the mothers’ themselves, reframed the concept of the burden of care will also be presented.

Chapter 6: will establish this study relative to its position on the issues of service provision and research in the Zimbabwean setting. Recommendations to the discipline of occupational science, the profession of occupational therapy and for further research are outlined.

1.10 Conclusion

Caring for a child with HIV-related NDD is unique in its own way because the carer has to deal with both the HIV/Aids issues and the disability that comes with an NDD. Moreover, if the biological mother is the one undertaking this caring role, she could be herself infected with HIV. Thus, occupational therapists need to understand the caring experience of the mothers caring for children with HIV-related NDDs, to provide appropriate support to the mothers.

Chapter 2. LITERATURE REVIEW

2.1 Introduction

This chapter reviews and critically interprets literature related to the experience of being a mother and caring for a child with an HIV-related NDD. Literature has been drawn from the different disciplines: Occupational Science, Sociology, and the professions of Occupational Therapy, Nursing and Psychology. Attached Appendix A: presents the databases and the search terms that were used to canvas the literature reviewed in this chapter.

The literature review revealed the paucity of research that has focused on the experiences of biological mothers caring for a child with an HIV-related NDD. Conversely the literature reviewed highlighted a dominant focus on caregiving for children with HIV/Aids by caregivers who were *not* their biological mothers (Kimani-Murage, Manderson, Norris & Kahn, 2010; Demmer, 2011). To support an extended overview of the available literature, literature on caregiving for children with disabilities outside of HIV-related NDD and chronic conditions (such as asthma) was also reviewed (Green, 2007; Bourke-Taylor *et al.*, 2009).

The literature is reviewed under the following sub-topics:

- Caregiving and caring framed as occupations of mothers;
- The contextual factors that shape the caregiving occupation;
- Occupation of caring by mothers of children who are chronically ill and/ disabled;
- Occupational therapy interventions for caregivers of children.

2.2 Caregiving and Caring framed as occupations of mothers

Occupation is essential across the human life course and it is a core concept of occupational therapy (Wilcock, 2006). Occupation has been defined as “...*ordinary things that people do every day and the way they spend their time, energy, interests and skills in meeting their needs...*” (Townsend & Wilcock, 2004; p. 244). Caregiving can be framed as an occupation that is predominantly done by mothers. Larson (2000) stated that mothers devote their time to caring for children and are involved in occupations geared to meet the demands of parenting.

Caregiving is an occupation that is central to the mothers' identities (Phelan & Kinsella 2013). Engaging in the caring role constitutes an opportunity for mothers to generate meaning and construct their individual identity as a mother and carer of the child with. From the studies that Vallido *et al.* (2010) reviewed in their narrative synthesis of mothering disrupted by illness, they discovered that many women view mothering as a source of pride, identity and achievement. An opportunity to care for one's own child was important and mothers were committed to caring, despite their own ill health. Demmer (2011) discovered that caregiving in South Africa was dominated by mothers and grandparents who were motivated towards the caring role.

In Africa, caregiving is a social role and women are viewed as natural caregivers (Hejoaka, 2009). The occupation of caregiving and caring for a child is shaped by socio-cultural norms that dictate the roles and expectations to be met (Njororai & Njororai, 2013). This view has been reiterated by Kuo and Operario (2009) who, in their systematic review on caring in Aids-orphaned children, also found out that the cultural norms compel women to be the carers. These studies highlighted how African society came to accept and expect mothers to provide the primary care for children. It is the need to achieve the identity of being a mother, as well as the cultural expectations of who should provide care to children that leads mothers into the caregiving occupation.

2.3 The occupation of caring by mothers of children who are chronically ill and/ disabled

This section unpacks the occupation of caring as it relates to mothers who are caring for their own children who are ill and/or disabled, with specific attention given to literature focused on the care of children who are HIV-positive with NDD. The section explores the various tasks associated with caregiving role of mothers, highlighting both the meaning ascribed to this occupation and the burden associated with engaging in the caregiving occupation. The section further highlights the ways in which contextual factors have been described as shaping the experience of the caregiving occupation, as well as how each mother's engagement in caregiving has been shown to shape her engagement in occupations other than caregiving.

Caregiving is an occupation that can be short-lived or, in the case of chronic conditions such as HIV-related NDD, can last for many years (or even a lifetime) (Moghim, 2007). The occupation of caregiving involves physical, medical, emotional, material and financial care

(Hejoaka, 2009). Levels and complexities of care will differ, depending on the age and stage of development of the child. Caregiving is even more demanding when the child does not achieve expected physical and psychological milestones (Nicholl & Begley, 2012). In the African context, the provision of care consists of domestic chores (such as cooking, cleaning, carrying water and firewood) as well as taking care of the children (Hejoaka, 2009).

The caregiving role for children with HIV/AIDS is extended because that care is not only limited to domestic care but also involves health work. When children have episodes of illness, health work would include administering of medication, feeding and, at times, wound dressings. These activities take place over and above the daily routines of care (Van Graan *et al.*, 2007). Mothers adapt and adjust their everyday occupations to accommodate the caring role, especially for a child with NDD. Adaptations include planning and juggling every day routines in ways that provide a balance between the needs of the child and other family members. A child with NDD would require the caregiver to not only accompany the child for frequent hospital visits but also to be in touch with the school (in the event that the child was attending school). Larson (2000) stated that caregiving for children with disabilities would require modification of daily routines to accommodate for the meetings and reviews with professionals in the educational and health care systems involved in the care of the child.

The burden of caring for a child with other chronic diseases (such as cerebral palsy and autism) is well documented (Green, 2007; Nicholl & Begley, 2012). Research reports that the burden of caring for children with HIV/AIDS is substantial and often wears down the carer (Sherry & Martin 2010). This was reiterated by Moghimi (2007) who, in her article on caregiving issues in occupational therapy, pointed out that the demands associated with caring for a child with a chronic disease affect both the child and the mother, often wearing down even the most capable of mothers. It is thus assumed that caring for a child infected with HIV and NDD is likened to that of caring for a child with a chronic illness. The chronic illness may also be associated with the prolonged provision of physical, mental and emotional support to the child and can also negatively affect the overall health of both the child and their mother.

Mothers worry about the negative impact of their disease on the child and this worry is exacerbated by their uncertainty about the progress of the HIV-related illness (D'Auria, *et al.*, 2006). The psycho-social stressors (such as depression, anxiety and fear of the uncertainties associated with HIV) often hinder the ability of the mother to provide the necessary child care

(Kuo & Operario, 2009). The mothers' feelings of guilt affect the performance of their caring role. A study done by Bauman, Silver, Draimin and Hudis (2007), on children of mothers with HIV/AIDS, highlighted that several of the mothers experienced activity restrictions because of their health several developed depression and anxiety.

In most cases the mothers of children with HIV-related NDD are themselves HIV-positive and at times they also experience ill health. Doare *et al.*, (2012) stated that often a mother's physical ill health hindered their ability to care for and stimulate the child. Simultaneously the demands that came with caring for a child with HIV-related NDD have the potential to negatively impact and worsen the mother's health. This was supported by Nicholl and Begley (2012) who stated that caring for children with complex needs requires the absolute involvement of mothers – which can result in sleep deprivation, disturbance, feelings of exhaustion and emotional turmoil. This burden of care can lead to depression, societal rejection, reduced quality of life, social stigma, grief and sadness (Bourke-Taylor *et al*, 2010). This in turn may lead to impaired attachment between the mother and child which, in turn affects the developmental potential of the child. Ramugondo (2004) in her anecdotal study on the interactions between HIV positive mothers and their children attending a health clinic in South Africa, reported that bonding between mother and child was affected and mothers' could not engage in play with their children. She reported that mothers were disconnected from their children because the mothers feared that their children would not live for long and thus they were fearful of getting too close emotionally.

Mothers of children with HIV-NDD first have to deal with the stigma that comes with her own HIV diagnosis and that of their child/children before they can overcome the burden of caring for a child with a neurodevelopmental disorder. Hejoaka (2009, p. 870) stated that the *“HIV/AIDS-related stigma adds an additional layer to the burden of caregiving, compelling mothers to deal with the tension between the secrecy surrounding the disease and the openness required in providing care and receiving social support”*. Because of HIV/AIDS stigma, the mother may also have limited social support – they carry an immense burden of caring for children and sometimes other family members who themselves may be infected with HIV. Many women living with HIV/AIDS must cope with discrimination, poverty, psychological distress and violence, alongside other things (Demmer, 2011).

Despite the negative effects, caregiving generates positive experiences, which mobilises caregivers to continue their support (I-Fen, Holly & Hseueh, 2010). A study in South Africa by Sungh *et al.*, (2011) revealed that caregivers, in home-based care tending people living with HIV/AIDS, experienced low levels of caregiver burden and showed willingness to care for another person. This is supported by Larson (2009) who noted that greater caring demands on mothers do not diminish their wellbeing and, when these demands have been successfully met, the mothers' positive mood is bolstered. A sense of fulfillment and being responsible is experienced when people find themselves being able to care and provide for another human being, especially children (Demmer, 2011).

Engaging in the occupation of caregiving offers an ideal channel for the realisation and application of human potential. Caregiving as an occupation presents challenges and opportunities which mothers can use to create and transform their lives, pursue aims, overcome barriers, learn new ways of achieving health and happiness and also discover purpose in life (Kuo, 2011). Participation in occupations that are meaningful, contributes to one's construction of identity (Phelan & Kinsella, 2013). Generally people engage in occupations that are meaningful (Kielhofner, 2008) and engaging in caregiving as an occupation can be a source of meaning for the mother or, inversely, the mother can generate meanings from the occupation itself (Aiken, Fourt, Cheng, & Polatajko, 2011). There can be situations where mothers are engaged in the caring occupation, not because it is meaningful to them, but where the occupation has been forced by circumstance. However, meanings can emerge from the experience and process of engaging in the occupation. Carers may be motivated to care through feelings of affection and cultural obligations (Moghimi, 2007). A sense of fulfillment and being responsible is experienced when a mother finds herself being able to care and provide for another human being, especially if the human is still a child (Demmer, 2011).

In shared meaning, an element of co-occupation emerges. Co-occupation has been defined by Piece (2003) as occurring when two or more individuals are reciprocally engaged in purposeful and meaningful occupations. The aspects of shared physicality, emotionality and intentionality that characterise co-occupation, as proposed by Pickens & Pizur-Barnekow, (2009), can be identified within caregiving. Therefore, the occupation of caregiving cannot be fully understood without looking at the reciprocal relationship between the mother, who is the carer, and the child. The co-occupation of mother and child is imperative to the child's growth and

development; the pleasurable and meaningful caregiving experience, impacting on the mother, contributes to her personal health and, reciprocally, to the child's health (Price & Miner, 2009).

Townsend *et al.*, (2009) highlighted that an occupation has a transformative potential on individual's health if the individual has the choice to choose and engage in meaningful occupations for the purposes of realising their personal dreams. Often people who undertake caregiving did not choose to engage in this occupation; it was thrust upon them by circumstances, usually beyond their control (Moghim, 2007). This could be true for mothers caring for children with HIV-related NDD, because most of them may only have found out about their own HIV status (and that of the child) during pregnancy and delivery (D'Auria *et al.* 2006). In most cases, situations of a loved one falling ill or encountering a disability often come without planning. Unfortunately, mothers do not have time to prepare and adjust to the challenges concomitant with caring for the child diagnosed with HIV-related NDD.

Mothers undergo a process of adjusting and adapting their mothering role to meet the caring needs of the child. In a study by Hejoaka (2009) in Burkina Faso, it was noted that the announcement of child's illness to the mother resulted in the re-organisation of daily events and social relations. As individuals take on the caring role, many changes happen (as they give up participation in previous occupations, roles and routines) to embrace new caregiving demands (Moghim 2007). Many caregivers may be compelled to quit meaningful occupations (such as productive work), which provide identity, social contacts and financial gains and, as a result, risk social isolation and endless childcare tasks (Ludwig *et al.*, 2007). Thus, the mother could become a victim of occupational injustice; she may be deprived and alienated from being able to engage and participate in commonly accepted occupations. Occupational injustice occurs when occupational determinants such as poverty, gender and unemployment limit participation in meaningful occupations. Townsend and Wilcock (2004) presented four cases of occupational injustices which are occupational imbalance, deprivation, alienation and marginalisation.

The above section details the various facets of the caregiving occupation, foregrounding caregiving as an extended occupation for mothers of children who have chronic illness or disability (including health work tasks which adds an additional layer to the more common tasks associated with caregiving). The meaning assigned to caregiving, as well as the burden of and the positive associations with caregiving, are highlighted. These contrasting aspects

further motivate the need for an in-depth exploration of both the positive and negative experiences of mothers who care for children with HIV-related NDD.

2.4 Contextual factors that shape the caregiving occupation of mothers of children with HIV-related NDD

The relationship between context and occupation has been widely conceptualised in occupational therapy literature (Kuo, 2011; Kielhofner, 2008). The word ‘environment’ is used interchangeably with ‘context’ in occupational therapy literature. The environment includes the physical, social, cultural and political aspects (Dickie, Cutchin, & Humphry, 2006) that effect day-to-day functioning of an individual. Cutchin, *et al.* (2008) stated that occupation provides a medium through which humans transact with the environment. In adopting this view, the experience of caring for a child with HIV-related NDD is shaped by the context/s in which they interact and, inversely, the context is influenced by the occupations in which they, the mothers, engage.

Hammel (2007) highlights that the ability to choose occupations can be constrained or made possible by personal circumstances, environmental barriers or societal pressures on the basis of gender, class, race, religion, education, ethnicity, culture and geographic location. This is supported by Galvaan (2012) who states that the process of choosing and undertaking the occupations is surrounded by a myriad of factors (in this case, the feminine gender as well as being the biological parent of the child with NDD positioned mothers with no other choice but to take care of their children). According to Townsend and Wilcock (2004) occupational deprivation arises when populations have limited choice in occupations. Thus, the interplay of both personal and contextual factors has a risk of predisposing mothers to various forms of occupational injustices.

Various contextual influences that are considered as shaping the mothers’ experiences of caring for their children, will be discussed under the following sub-section headings (as drawn from the literature reviewed).

Poverty

The multidimensional relationship between HIV/AIDS and poverty is indisputable (Mbirimtengerenji, 2007; Sherry & Martin, 2010). Many HIV-infected mothers are young, and

single, parents who live in poor housing and who have to contend with financial difficulties (D'Auria *et al.* 2006). Chances are high that the mothers providing care for a child with HIV-related NDD are doing so in a poverty-stricken environment and this increases the burden of care. Moreover, in Zimbabwe, it is reported that the majority of people still live in poverty (despite the positive economic recovery currently being experienced).

Demmer (2011) in his study of the experiences of families caring for an HIV-infected child in KwaZulu-Natal, South Africa, contended that the burden of caregiving is exacerbated by extreme poverty, stigma, lack of support and lack of responsibility offered by other members of the household. He further noted that the burden is also influenced by social and cultural norms – which manifest in inadequate support, coupled with multiple family demands. Caring experience is associated with challenges that include increased financial pressures, limitations in caring for other biological children and other household members and work conflicts (Kuo & Operario, 2009). The burden of care is even greater in resource-poor settings (UNAIDS, 2008) where the mother (carer of the child) will need to go out of her way to provide both for the child and for other family members under her guardianship.

A study by Hejoaka (2009) indicated that most mothers were the heads of the family and were engaged in informal trading activities to provide a measure of income for the household. The informal trading activities imposed time constraints that were incompatible with children's medication schedules. HIV impacts on the economically active members of the society, taking them out of the labour force to take care of the sick relatives. This inevitably reduces the income on which the family depends. Health care costs often eat up the hard-earned family finances further reducing funds available for schooling, informal enterprise income and other occupations – all of which have the potential to take the household out of poverty (Sherry & Martin, 2010).

Poverty creates an environment in which HIV thrives and cyclically HIV plunges individuals deeper onto poverty (Sherry & Martin, 2010). The complications that arise as a result of HIV add to the caring demands and the financial burden linked to providing everything the child needs is vast (UNAIDS, 2008). People infected and affected by HIV/Aids are at risk of living in severe poverty. People with disabilities experience higher rates of poverty than non-disabled people, and may have to bear extra costs for personal support or for medical care or assistive devices (WHO, 2011). This would be of significance for the children with HIV-related NDDs

who need regular medical attention. The intersectionality of having HIV and any disability predisposes mothers and their children to poverty.

In linking poverty to occupation, Watson & Lagerdien (2004) described poverty as having an inevitable impact on engagement in self-initiated, self-directed, adaptive, purposeful and culturally relevant organised occupations. Duncan (2009) highlighted the paucity of literature that examines the impact of poverty on the occupations in which people engage. This research study addresses this gap by exploring the lived experience, of being a mother and caring, in contexts where poverty intersects, in a variety of ways, to shape the occupation of caring for a child with HIV-related NDD.

Spirituality

The occupational therapy profession has embraced the centrality of spirituality in the engagement and performance of meaningful occupations (Farah & McColl, 2008). Spirituality plays a role in shaping and giving meaning to people's occupations. Occupational therapists enable people to engage in occupations that are meaningful to them. Hammell (2004) noted that people who have experienced life disruptions had spiritual concerns and often raised issues of meaning, values and purpose. This has been supported by Lin *et al.* (2013) who found that spirituality is an essential element of resilience and caregivers draw their power and strength from superior powers in the face of difficult scenarios. Spirituality can be used to find alternative meaning and optimistic explanations for life circumstances (Larson, 2000). For example, a mother can find meaning from engaging in caregiving because she believes that having a child with disabilities is a test from God. Thus, it is imperative to have a deeper understanding of spirituality in relation to occupations that people are engaged in every day – especially mothers caring for children with NDD.

Culture

Occupations are central to the identity and competence of people because individuals, groups or communities assign priority and meaning to occupations according to their culture, values and beliefs (Phelan & Kinsella, 2013). Mothers may be motivated to care by their feelings of affection and cultural obligations (Moghim, 2007). The caregiving occupation is a social role shaped by gender and women are generally identified as caregivers. In most societies it is often taken for granted that women have to take care for the sick – and particularly for children

(Hejoaka, 2009). Culture often defines the roles of the mother and assigns the role of caring for the young, old and or the sick to the mothers. Although the culture of interdependence is prevalent in Africa, mothers are still expected to take care of the children (Sherry & Martin, 2010). The particular influence of the Shona culture on the mothers' experiences of caring for their children will be explored in this study.

2.5 Occupational Therapy Interventions for caregivers of children with chronic illness and disability.

Despite the HIV/AIDS pandemic having existed for decades, a search for literature revealed the paucity of research on caregiving by biological mothers for children with HIV-related NDD, especially from an occupational perspective. Case-Smith (2009), in her editorial message, stated that occupational therapists' support for caregivers may not be clearly defined but is embedded in their everyday practice. Occupational therapy has broad expertise for intervening to facilitate people's positive occupational experiences, thereby to promoting their health and well-being. The occupational therapists use their knowledge and skills to improve the physical, psychosocial, cognitive, sensory and contextual elements that affect the person's participation and engagement in occupations (O'Sullivan, 2007).

However, Moghimi (2007) highlighted the need for occupational therapists to consider how they can support and empower caregivers to engage in their caregiving occupation in ways that will not only improve their performance of caring to benefit the child, but also to build on ways that they can continue to derive meaning from engaging in the caregiving occupation. Bourke-Taylor *et al.*, (2010) conducted a study on understanding the mother's perspectives of caring for school-aged children with different disabilities in Canada. Their recommendations indicated that there is need for client-centred, goal-oriented interventions to address the co-occupation between the mother and child. Interventions must involve assisting mothers to understand and accept their child's disability, to rationalise ways to overcome various challenges and to seek and obtain support from others.

Cocoran and Donovan (2010) reported that most occupational therapy caregiving intervention is problem-based, designed to teach caregivers how to compensate for physical and cognitive deficits, ease the burden of care, provide more effective supervision or strengthen coping behaviours. This might be because overwhelming attention has been given to the negative

aspects of caregiving at the expense of the positives (I-Fen, *et al.*, 2010). Thus, therapy could be missing an opportunity to provide interventions that directly help caregivers emphasise and act on the positive aspects of caregiving (Cocoran & Donovan, 2010).

In addition to problem-based interventions, occupational therapy practitioners help to ensure a healthy and balanced lifestyle for caregivers who either experience sudden or long-term changes or may be at risk of negative health consequences. Also, the occupational therapist facilitates the caregiving occupation by removing barriers (physical and psychological) through creating a platform for discussion, for learning and by providing reassurance to parents (Case-Smith, 2009). This involves re-framing the mothers' perceptions of the child and the overall caregiving occupation. Ramugondo (2004) created an intervention, which combined an understanding of the needs and the impact of stress on caregivers of HIV-positive children, in Cape Town, South Africa. Workshops with caregivers, held by Ramugondo, offered a platform for caregivers to discuss, share and learn from each other, thereby engaging caregivers in a process of reframing their own perceptions of the child under their care. Previously the perception of the child as 'sickly and going to die' had affected the bonding between the caregivers and the children. One of the outcomes of these workshops was the way engagement and bonding – of caregivers with their children – was encouraged. Play was to be used as a means and medium and, inversely, these three factors improved the caregivers' performance in caregiving.

Occupation performance coaching (Graham, Rodger & Ziviani, 2009) is another intervention used by therapists for identifying issues that are barriers to the performance of the parenting role. Specific language, questioning and reflection cues are used to guide parents towards discovering solutions, their implication and evaluation within a problem solving framework (*Ibid*). This approach is of relevance to caregiving mothers, who have to deal with stigma, poverty and other burdens that are associated with HIV (Sherry & Martin, 2010). Occupation performance coaching recognises the co-occupation of the mother and child in daily occupations and empowers the mother to solve problems and improve their own performances for both participants.

2.6 Conclusion

This chapter has reviewed literature relevant to caregiving as an occupation in the context of HIV/Aids. The review highlighted the burdens associated with caregiving and the subsequent risks imposed on mothers caring for children with disabilities, with a particular focus on caring for children with HIV-related NDD. The view and understanding of caregiving as an occupation, that forms part of and interacts with contextual factors, has also been highlighted.

Despite the negative associations of the caregiver burden, the literature also pointed out that caregiving is an occupation that is and has the potential to be meaningful and fulfilling to the mothers. Despite this, the literature indicated that most occupational therapy interventions to caregivers are problem-based and not based on an in-depth exploration of mothers' lived experiences of caring for their HIV-related NDD children. Thus there is need to develop an appropriate approach specifically for intervention with mothers who are caring for children with HIV-related NDD. The first step towards developing the intervention model is to gain an understanding of the caring experiences of the mothers. The review has confirmed the need to understand the lived experience of caring for a child with NDD, with particular attention to how this occupation is experienced from the occupational perspective of the mothers as caregivers.

Chapter 3. METHODOLOGY

3.1 Introduction

This chapter gives a description of the research methodology used in this study. It begins by justifying the chosen approach and design and then explains the research process, giving a detailed account of participant selection, data generation methods, and the analytic and interpretive procedures. The chapter closes with a description of the ethical considerations and their application.

3.2 Research design

A qualitative research approach was employed because it allowed the researcher to obtain invaluable in-depth information about caregiving from the mothers' perspectives. The researcher set out to gain an understanding of the biological mothers' lived experiences of caring for children with an HIV-related neurodevelopmental disorder. Qualitative research provides the individuals with a voice to relay their unique experiences in a way that they can be well represented and understood (Silverman, 2006).

A descriptive qualitative study using a hermeneutic phenomenological approach was used to elicit and understand how the taken-for-granted phenomena – such as engaging in the everyday occupations usually associated with being a caregiver of a child with an HIV-related neurodevelopmental disorder – are lived and experienced (Lala & Kinsella, 2011). Hermeneutic phenomenology seeks to uncover the phenomena, thus allowing the researcher to understand and describe the caregiving occupation. Phenomenology is an approach in qualitative research that is increasingly being used by occupational therapists as an approach congruent with occupational therapy values concerning the uniqueness of an everyday experience, the meanings drawn from the experience and the context of the mothers' environments (Savin-Baden & Major, 2012). The approach allowed the researcher to focus on the 'life world' of the mothers, and the essence of caring for a child with HIV-related NDDs. The phenomenological approach also allowed the researcher to see things through the eyes of the mother and to provide a description of how mothers' experienced the caregiving occupation (Creswell, 2007).

3.3 Research Setting

The study sample was recruited at Harare Central Hospital, Children's Rehabilitation Unit (CRU). The CRU is the main referral center for children with disabilities in Zimbabwe. The CRU was established in 1986 as a joint project between the Department of Paediatrics, University of Zimbabwe, and the Department of Rehabilitation in Zimbabwe's national Ministry of Health and Child welfare. The main objective of the CRU is to provide accessible, comprehensive rehabilitation to children; services offered include physiotherapy, occupational therapy, workshops and group counselling, medical clinics and parent training (Birdthistle, Floyd, Mwanasa, Gwiza, & Glynn, 2011).

Alongside the other service delivery systems, CRU has an outreach team and conducts workshops for caregivers and their children. The outreach team goes out into the community to offer various services. Activities offered through the outreach programmes include: assessments and screening; educational sessions for the caregivers and individual therapy sessions for the children. Caregivers and their children with disabilities gather at their local suburban community centre twice a month to attend the CRU outreach clinics.

Workshops are held once each month at the Harare Central Hospital's CRU unit and various topics are covered. The workshops are designed for specific groups of caregivers and their children. Through permission from the Matron-in-charge of CRU, the researcher attended a workshop for mothers living and caring for children with HIV-related disabilities at the CRU unit a month before starting data collection. The week-long workshop covered different topics including: living with HIV/AIDS; PMTCT; nutrition and the impact of HIV on child with disability among other issues were also presented. There were also discussion sessions where mothers shared their experiences and were able to express their feelings about caring for a child both infected with HIV and having to cope with a disability.

On attending the workshop, the researcher was introduced as a mother who was also a visitor to CRU. Because in the Shona culture, mothers are usually identified by the names of their children – for example 'mai Anna' (mother of Anna) – the researcher was also named in a similar manner as 'mai Kunaishe'. This allowed the researcher to build rapport and establish familiarity with this group of mothers. The researcher met and interacted with the mothers of

children with HIV-related NDDs at this workshop before data collection. The researcher also took the opportunity to identify potential participants to recruit for this research study.

3.4 Participants selection

Non-probability purposive sampling was used to select biological mothers caring for children with HIV-related neurodevelopmental disorder. Purposive sampling involves deliberately selecting particular settings, events or persons for the in-depth information they can provide, which cannot be obtained from other sources (Creswell, 2007). To gather information that would enable a deeper understanding of participants' experience of the caring phenomena to emerge, it was necessary to select mothers who had a lived experience of caring for a child with HIV-related NDD and were willing to express and share these experiences with another person. Also, in a phenomenological study, the participant or person being interviewed is often the primary source of data (Creswell, 2007).

Patton (2002) stated that any common patterns emerging from great variation are of particular interest and value for capturing the core experiences and centrally shared aspects or impacts of a programme. The researcher employed maximum variation to capture diverse variations of the mothers' experiences. In this study, the sampling process ensured the selection of mothers of differing ages, marital status and educational levels. These mothers also had different numbers of children of differing ages, thereby increasing maximum variation. Patton (2002) stated that maximum variation involves searching for individuals who cover the spectrum of positions and perspectives in relation to phenomena being studied.

The selection of participants for the study was also guided by the criterion outlined below.

3.4.1 Inclusion Criteria

- Mother who was the primary carer of the child diagnosed with HIV-related neurodevelopmental disorder;
- Mother whose child was less than five years of age and receiving rehabilitation services at Children's rehabilitation unit. (Children of ages five and below receive free treatments at government hospitals (such as the Harare Central Hospital) where the CRU is based);
- Mother who was able to read and write either Shona or English;

- Mother who was willing to participate and gave informed consent.

3.4.2 Exclusion Criteria

- Mother and child dyads that had been treated by the researcher prior to the study (the past therapy interactions of the mother and the researcher could bring some bias into the findings);
- Mother who had physical and/or psychiatric conditions significantly affecting their occupational performance and ability to participate in the study (these problems would have a bearing on the mother's experience of caring).

3.4.3 Sample size

Initially six mothers were selected, one for the pilot study and five for the main study. However, one of the five mothers selected for the main study was excluded because her child had Down's syndrome, which is not a HIV-related neurodevelopmental disorder but a chromosomal disorder. A final total of five participants were selected for the study. Creswell (2007) stated that in qualitative research employing in-depth interviews; five to ten subjects in a study represents a reasonable size.

3.4.4 Procedure of Sampling

Permission to carry out the research at CRU was first requested from the Matron-in-charge. Apart from extending an invitation to the researcher to attend the caregivers' workshop, the Matron also introduced the researcher to the CRU administrator who assisted in the recruitment of the participants. Records of children with HIV-related neurodevelopmental disorders were sourced from the Harare Central Hospital Children's Rehabilitation Unit's administration office. Through the assistance of the administrator, children whose biological mothers were registered as primary caregivers were identified and listed, including their demographic details. A list of fourteen mothers who met the selection criteria was obtained. Using the maximum variation criteria, five mothers were selected for the study.

The administrator has regular contact with the mothers and often is the one who calls mothers to invite them for workshops and reminds them of their appointments. Because of the

sensitivity of HIV issues and the existing structures at CRU, the researcher felt it was most appropriate for the administrator to contact the mothers first. The administrator telephoned the mothers, briefed them about the research and facilitated the initial appointments between researcher and the participants at CRU. The appointment dates were coordinated with each mother's visit to the CRU.

Mothers were encouraged to leave their children in the play room under the custody of 'gogo' (the nurse aid). This play room is part of an existing structure of support and care for children, used by the caregivers when they attend the CRU family clinic. The researcher was in the group discussion room, and mothers came in for their personal interview separately. The researcher welcomed each of the mothers and went through the information letter (Appendix B:) with each of them. The information letter was written in English and Shona (the two predominant languages spoken in Harare). The researcher, who is fluent in both languages, gave mothers an option to choose which language they were comfortable to use. The information letter gave clear details about the research process, purpose, benefits and risks of taking part in the research. Once the mother had agreed to take part in the research, she was asked to fill in the informed consent and give contact details (Appendix C:).

All the selected and contacted mothers agreed to take part in the study. The researcher discussed and made an appointment with the mother, either at the CRU or at another venue (free from noise and distraction) and at a time convenient to her. Most of the mothers felt that the CRU was a good place for the interviews. Mothers set dates for the interview which did not coincide with their appointments at the CRU clinic. Thus, mothers were reimbursed for their traveling costs for the day of interview when they did not have appointments for treatment at the CRU.

3.4.5 The Participants

Five participants who are all biological mothers caring for their children with HIV-related neurodevelopmental disorders were purposively selected for the study. A phenomenological approach emphasises placing value and respect for the participants as key informants in the research process, thus as a sign of respect the researcher undertook to call the participants "mother". In the African culture calling a married woman "mother" is a sign of respect and there is dignity attached to it (Akujobi, 2011).

Table 3-1 shows the demographic data of the mothers. To maintain confidentiality all participants were identified with pseudonyms throughout all stages of the research. All the mothers included in the research were literate (able to read and to write). One of the mothers had a Primary School level of education, one had High School up to Form Two and three had managed to complete the four years of Secondary education. Mothers' ages ranged from 25 to 40 years. Although the mothers came from different suburbs (locations), all the locations were from high density suburbs. This was because the Harare Central Hospital CRU, where the mothers were recruited, mainly serves residents from high density suburbs. People from other districts, who are initially referred to Harare Central Hospital, are referred back to their local clinic once they are in a stable condition. Thus it was difficult for the researcher to include mothers from other districts in the study.

Socio-economic status was assessed, based both on researcher's knowledge of local conditions and what the participants reported during the interview sessions. Two mothers were poor and the other three had an average socio-economic status. Three of the five mothers were not involved in any productive occupation – that is they were not involved in any activities that could provide them with regular income. The other two were also not formally employed but were involved in buying and selling different commodities. All the mothers stayed in rented houses; some shared the houses with other families, thus using only one or two rooms.

The children had different neurodevelopmental disorders which included cerebral palsy, delayed developmental milestones and left hemiparesis. One mother had two children who were both HIV-positive but only one of these two children had an NDD. Another mother had one child and that only child was the one diagnosed with HIV-related NDDs. Two mothers had two children each and of these the first-born were HIV-negative and the youngest sibling was HIV-positive with NDDs. The last mother had three children and of these only the last-born was HIV-positive with NDDs; the other two were HIV-negative.

Table 3-1: Demographics of Participant Mothers

Mothers	2 (Tinashe)	3 (Memory)	4 (Nomsa)	5 (Kudzi)	6 (Zivai)
Age of mother	35	33	40	25	30
Marital status	Married	Married	Married	Single (separated)	Married
Level of education	Form 4	Form 2	Grade 7	Form 4	Form 4
Suburb/location	Budiriro	Glenview 3	Old Tafara	Kuwadzana	Dzivarasekwa
Occupation/employment/work	Not working	Not working	Not working	Buying and selling of goods	Buying and selling of meat
Economic status	Good (husband is an engineer)	Poor (both parents do not work)	Average (husband is a welder, his job is not well-paying)	Poor	Average (husband works in a supermarket)
Number of children	3	2	2	1	2
Ages of the children	9; 5; 3	6; 4	16; 2	2	5;3
HIV Status of the children	First two are negative and only last born is positive	Both are positive	First born is negative and second is positive	Child is positive	First child is negative and the second is positive
Children with NDD: type of disability					
Disability	Delayed developmental milestones	Epileptic/ left hemiparesis	Cerebral Palsy	Cerebral Palsy	Delayed developmental milestones
Age (years)	3	4	2	2	3
Gender	Male	Male	Female	Female	Male

3.5 Data collection Schedule

Data collection was done between May and October 2013. In May 2013 the researcher was in Harare, Zimbabwe, and managed to undertake the procedure for selecting, contacting and asking for informed consent from participants. The researcher also took that opportunity to familiarise herself with the CRU staff and structure and to attend the mother's workshop.

During the month of June 2013 first line interviews were conducted, recoded and transcribed. The month of July 2013 was dedicated to the analysis of the data from first the interviews and setting the agenda for second interviews. Analysis of data was done in Cape Town with a debriefing and audit trail from the supervisors. In August 2013 the researcher went back to Harare and carried out the second line interviews, which were analysed and written up during the month of September 2013. In October 2013, the processed data, which was a combination of analysis of interview one and interview two, was returned to the participants for member checking. Mothers were given the opportunity to go through the analysed data and share their views on the data with the researcher. All the mothers agreed that the data was a true reflection of their caring experiences.

Table 3-2. Data Collection Schedule

Month and Year	Action
May 2013	Participants' selection. Researcher attended workshop for mothers living and caring for children with disabilities at CRU
June 2013	First line phenomenological conversations
July 2013	Analysis of data from first interviews and agenda setting for second interviews
August 2013	Second line interviews
September 2013	Analysis of Data from first and second interviews
October 2013	Third interviews for member checking

3.5.1 Data collection methods

A one-to-one, in-depth phenomenological interview technique was employed to explore the lived experience of mothers caring for children with HIV-related neurodevelopmental disorder (Chan, Williamson & McCutcheon, 2009). Interview is the most common method of collecting data in qualitative research (Savin-Baden & Major, 2012). It was through an in-depth interview that the experiences and the feelings of mothers were described and explained in a way that allowed the researcher to see things from the mother's point of view. The phenomenological interview gave an opportunity for the interviewee to raise issues around the caring phenomenon

that she felt to be important. This also allowed the researcher to explore these issues in detail. Basically, the interview was a conversation conducted with the purpose of developing an understanding of the lived experience of caring for children with HIV-related NDDs.

Interviews were guided by open-ended questions, derived from the objectives and literature review (Appendix F:). The interview guide was taken to the Human Research Ethics Review Committee (HREC) for approval before use. The guide was composed of six open-ended questions used to assist the researcher during the interview process. A pilot interview was used to refine the interview guide questions. The researcher probed discussion by following up ideas raised by the mothers. Open-ended questions allowed the researcher to explore the mothers' perspectives on topics or issues they raised (Savin-Baden & Major, 2012).

To enhance data collection; mothers were provided with a journal at the end of their first interview, which they used to write down their feelings, thoughts and interpretations of the interview. This journal contained a copy of the set of questions asked in the first interview. The journal served as a tool which the mothers used to reflect on the questions asked in the interviews (Creswell, 2007). The mothers represented in words (and/or pictures) their reflections of the first interviews and included any other information they thought of as important. The journal was thus used as a tool that mothers could use for reflection purposes after the first interview and was collected at the beginning of the second interview for analysis by the researcher. Information from the mothers' journals was also included in the findings.

The researcher also made use of a research journal throughout the study period. The journal was used to record what happened, the meanings derived, reminders, instructions or critiques and progress reports at end of each day of data collection. Thoughts, feelings and interpretations of the interviews were written down as a way of reducing researcher bias (Creswell, 2007). The research journal also served as a detailed audit trail because it was used to document decision-making processes related to the research process.

3.5.2 Pilot Interview

A pilot interview was done with the first participant to refine questions for the in-depth interviews, as well as to determine the amount of time required for each interview. Also, the interviewing required that the researcher had deep listening skills and was skillful at personal

interaction, question framing and gentle probing for elaboration, (Savin-Baden & Major, 2012). The pilot was also used as a platform to practice the interview skills and build the confidence of the novice researcher. One mother was selected at CRU clinic for the pilot interview.

From the pilot interview, it was noted that the interview would last approximately 90 minutes. The mother had no problems in understanding and responding to the questions. No changes were made to the interview guidelines. The mother then became part of the larger sample and data from the interview was included in the data analysis.

3.5.3 Procedure of data collection

As phenomenology entails, the researcher collaborated with the mothers with the intention of both evoking a colourful description of the caring phenomenon and developing an empathetic understanding of the ways in which mothers experienced the caring occupation (Savin-Baden & Major, 2012). The researcher built rapport with the mothers during the workshop period and in the first meeting – when the participants were asked for informed consent to participate in the study. Also, mothers were given an opportunity to decide on a convenient place and time the interviews were to be done. The location could be in the participants' home, CRU clinic or any other quiet, convenient venue, mutually agreed to by the mother and the interviewer. All the mothers felt the CRU to be a convenient place for them to meet with the researcher. Thus, all interviews were carried out at CRU.

The interview room was a spacious office, free from distractions. Comfortable chairs were arranged to avoid a face-to-face confrontational position but allowed the mother to freely narrate and share her experience with the researcher. Most mothers preferred being interviewed with their children present and provision for that was made. A mat and toys for the child to be playing as the interview progressed were made available. At times the interview would be conducted on the mat as mother wanted to be very close to the child or if the child was irritable. This ensured that the mother was comfortable and able to give information freely without distraction (Creswell, 2007). Refreshments for both the mother and the child were served during the interview.

All interviews were conducted by the researcher if only to ensure that an in-depth essence of experience was consistently maintained by a single interviewer. At the beginning of the interview session, the tape recorder was started and checked for recording. The researcher posed probing questions to the mother. On average each interview lasted between 60 to 90 minutes. At least two interview sessions were carried out with each mother during data collection stage. Data from the first interviews was transcribed and analysed before the second interview stage. Analysis of the first interview transcripts before the second interviews allowed the researcher to gradually uncover core themes within the phenomenological interviews (Savin-Baden & Major, 2012). The analysis also helped the researcher to prepare adequately for the follow-on interviews. Guidelines for the second interviews emerged from this analysis. The guidelines were issues the researcher wanted to have clarified and/or explored in greater detail. (Appendix H:).

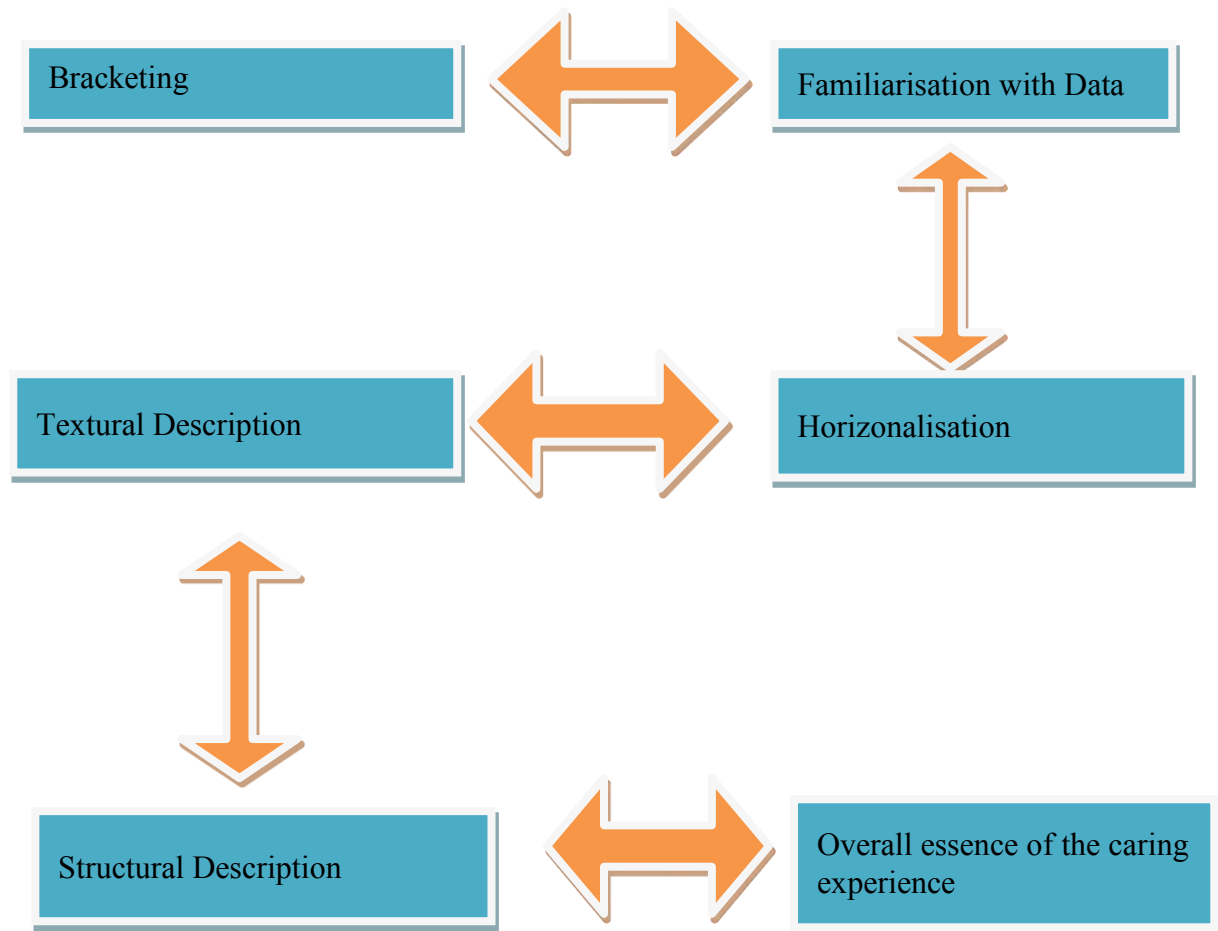
The third interview sessions were carried out for member checking purposes. Member checking was done to increase credibility, clarification and further explanations from participants (Lincoln & Guba, 1985). During member checking, a combination of analysed data from both interview one and two were brought to the mothers, who in turn reviewed it to ensure that the findings were a true reflection of what they had said. All the mothers agreed that the data was a true reflection of their caring experience of coping with an HIV-positive NDD child.

3.5.4 Data storing methods

All interviews were tape recorded with a digital voice recorder. Each interview was assigned a code and date to maintain confidentiality. At the end of the interviews, recordings were transcribed verbatim. Research journals used by the researcher and those journals used by the participants for reflective purposes were referenced to during the transcription and analysis of the data. Electronic data (audio-taped recordings and transcriptions) were stored on the researcher's work personal computer hard drive. Security codes were set to limit access to the data to researcher only. Backups were maintained on an external hard drive which was kept in a locked cabinet in the researcher's work-based office. Hard copies of data (journal articles and consent forms) were also securely locked in this same cabinet (one in the researcher's work based office). Only the researcher was in possession of the key set for this cabinet. All stored data will be destroyed six months after the end of study to maintain confidentiality.

3.5.5 Data Analysis Procedure

Figure 3.1: Data Analysis Process



Data analysis was guided by a simplified version of the Stevick-Colaizz-Keen method detailed in Creswell (2007) and Moustakas (1994). The data analysis procedure followed an iterative process whereby the researcher moved forward and between the different steps of the analysis to eventually describe and present the caring findings in a scientifically sound format. Steps followed are outlined in Figure 3.1

1. Bracketing

Bracketing – also referred to in some texts as Epoche (Creswell, 2007) – involves a process of identifying the potential biases and unconscious expectations of the outcomes of the study and then bracketing them out from the interview and analysis of the data (Savin-Baden & Major, 2012). In this research, the beliefs and assumptions of the researcher, drawn from her clinical

experience in regard to the caring phenomena under study, were declared. Bracketing limited the bias and contamination of the findings by the researcher's preconceived assumptions and experiences. Thus, the process of bracketing ensured that the findings of the study were a true representation of what the mothers had said.

The researcher is a qualified occupational therapist who has experience of working with mothers of children with disabilities in a cerebral palsy clinic for three years at the Parirenyatwa group of hospitals. However, at Parirenyatwa the focus of treatment was mainly on the child and not the mother. Treatment by an occupational therapist in the cerebral palsy clinic lasted 45 minutes to one hour. Because of the limited number of times the mother were able to visit the clinic and the high volume of patients, the occupational therapist assessed the child and demonstrated what the mother had to do at home. In other words, the mother was empowered to be able to continue with therapy at home, despite the other roles she had as a mother, caregiver, breadwinner and community member.

In dealing with these mothers, the researcher noted that mothers of children with disabilities linked to HIV were missing their appointments, were not enthusiastic with the treatment and several were not applying the home programme. However, the therapist was not in a position to explore further what the mothers were going through because of a high case load and limited the time the researcher was in contact with the mothers. This situation is the reason for the researcher developing an interest in understanding the mothers' lived experience of caring for a child with HIV-related NDD, so that support strategies and effective interventions could be formulated.

Although the researcher is also a mother, her experience of caregiving is different from those of the mothers who participated in the study. This is because of the difference in social class and also because the demands for caregiving to a child with HIV-related NDD are different from those of other children. In cognisance of these differences, the researcher had prolonged engagement with each of the mothers to develop an understanding of the mother's experiences. Bracketing and peer debriefing sessions with colleagues and supervisors allowed the researcher to hold back any bias through her own experiences and allow the findings to be a true reflection of the caregivers experiences.

2. Familiarisation with data

The researcher familiarised herself with the data by listening to audio recordings of the interviews, transcribing and translating the data into English and reading through the interview transcripts back and forth during the data analysis process. This allowed the researcher to immerse herself in the data and develop a deep understanding of the data as a whole as well as its component parts, (Savin-Baden & Major, 2012).

3. Horizontalisation

All significant statements describing the essence of caring for a child with HIV-related NDDs were recorded from the transcripts, after marking and highlighting them. Equal value was assigned to each of the significant statements in the process of Horizontalisation (Appendix I:). Significant statements were then grouped into larger units of information, called ‘meaning units’ or ‘themes’ where the statements appeared to convey similar meanings. An appropriate title was selected to capture the meaning of all the significant statements gathered in each group. If title did not accurately convey the intent of all the contributions within each theme, it was changed or the material was removed. Different colours and visual guides were used and this made it easy to see how different participant’s opinions were grouped in each of the themes (Savin-Baden & Major, 2012). The process was quite involved and the researcher took several breaks to ensure the data was reviewed with fresh eyes and to avoid any short cut biases that may have corrupted the data.

4. Textural Description

The researcher then engaged in a process of writing a description, called the ‘Textural Description’, of what participants in the study experienced with the phenomenon, including the verbatim examples.

5. Structural Description

The researcher also reflected on the setting and context in which the phenomena was experienced and wrote a description of “how” the caregiving experience had happened. This was called the ‘Structural Description’.

6. Overall essence of the caring experience

The Textural and Structural Descriptions were then combined to convey overall essence of the experience.

Data was analysed by the researcher alone. However the researcher had sessions of debriefing on a regular basis with colleagues from the masters' class and her supervisors. Data was continuously reviewed to confirm or discredit initial findings.

3.6 Data report and discussion

Findings were reported as 'themes' and categories that emerged from the data collection and analysis stages. Direct quotations from the mothers' interviews were also included in the reporting to substantiate the findings. The discussion draws on the findings of the study, interfacing these with the literature reviewed to frame a comprehensive description and deep understanding of the lived experiences of the mothers caring for their child/dren with a HIV-related NDD.

3.7 Scientific Rigour or Trustworthiness of the study

In this qualitative research, trustworthiness of the study was established by evaluating whether the elements of credibility, dependability, transferability and conformability were true for the study (Lincoln & Guba, 1985). Scientific 'rigour' or trustworthiness involves the researcher's ability to use appropriate, adequately replicable methods to clearly, and correctly report the findings (Krefting, 1991).

3.7.1 Credibility

'Credibility' refers to the researcher's efforts to establish confidence in the truth of the findings for the participants and the contexts, taking into account the existence of multiple realities, (Lincoln & Guba, 1985). Credibility was achieved through prolonged engagement with the mothers and staff at the Children's Rehabilitation Unit as a way to build trust and learn their culture before the collection of data. The researcher attended a week-long workshop on disability and HIV/AIDS that was being conducted for mothers caring for children with HIV-related disabilities at the CRU. Meeting and interacting with the mothers during the

workshop allowed the researcher to be familiar with the mothers' preferred way of doing things. The researcher also ensured credibility of the study by regularly holding peer review and debriefing meetings, either with her colleagues or her supervisors. Peer debriefing was conducted to keep the researcher honest. The searching questions arising in this process contributed to a deeper reflexive analysis (Lincoln & Guba, 1985). Peer review and debriefing was done throughout proposal, data collection, analysis and the write up stages.

Credibility also included member checking, which involved taking the data analysed, interpretations and conclusions back to the participants. Each of the mothers had an opportunity to go through the findings, with the assistance of the researcher, and during this process each mother judged the accuracy and credibility of the findings (Creswell, 2007). All the mothers agreed that the findings were a true reflection of their caregiving experiences.

3.7.2 Confirmability

'Confirmability' has been described by Lincoln and Guba (1985) as the degree to which findings are determined by the respondents and the conditions of inquiry are free from biases, motivations, interests or perspectives of the inquirer. The researcher ensured confirmability by declaring all of her background, interests and philosophical assumptions, that had potential to influence the research process through a strategy called reflexivity (Krefting, 1991). During data collection and analysis, the researcher undertook the process of bracketing; declaring and setting aside her experiences as much as possible, to take a fresh perspective toward the caregiving phenomenon (Creswell, 2007). Also, a research journal was used throughout the study to describe, interpret and critique her own behavior and experiences within the research context, ensuring she remained true to the research findings. The researcher also used the journal as a tool to critique and write reflections of the research process, thus enabling her to remain true to the research findings.

3.7.3 Dependability

'Dependability' refers to the consistency of the findings (Lincoln & Guba, 1985) and helps further to establish the trustworthiness of the study. Dependability of the research was achieved through an audit trail, which was included in the researcher's field journal. The audit trail included a daily schedule, logistics and methods logbook (Silverman, 2006). The audit trail

was maintained so that any colleague or peer, external to the research process but who has knowledge and experience in qualitative research, could monitor the status of the research at all stages to ensure appropriate decisions were being made throughout (Carpenter & Suto, 2008). The audit trail also helped to keep the researcher honest and contributed to the deeper reflexive analysis by the researcher (Krefting, 1991). In this study the researcher made use of research supervisors, who have knowledge and experience of qualitative research, to do an audit check. All details of the research process have been represented clearly in this thesis to ensure dependability was maintained.

3.7.4 Transferability

‘Transferability’ can be defined as the ability to transfer study findings described in one context to similar situations or participants (Carpenter & Suto, 2008). In this study, transferability was achieved through provision of a rich and detailed description of the study participants and their contexts. These detailed descriptions helped the researcher to capture the experiences of the mothers and make decisions regarding the transferability of the findings (Lincoln & Guba, 1985). Purposive sampling, which included the maximum variation of participants, was adhered to in an attempt to display multiple perspectives about the phenomena under study, thus ensuring richer findings applicable to other phenomena in similar contexts (Creswell, 2007). Despite this variation, the findings of this study would best be generalised as applying to mothers caring for children with HIV-related NDDs, from the ‘low-to-medium’ income strata of the population of Zimbabwe.

3.8 Ethical considerations

3.8.1 Introduction

The principle of ethical considerations have been adhered to; primarily to ensure that there has been a preservation of human dignity and the support of equality, truth and justice throughout the research process (Silverman, 2006). This study was reviewed at the Department of Health and Rehabilitation Sciences and received ethical clearance from the Faculty of Health Sciences, Human Research Ethics Committee (HREC REF: 182/2013) before data collection commenced. In Zimbabwe, where the data was collected, the proposal was sent for approval by the Medical Research Council and approval was granted (MRCZ/B/501). The permission

to carry out the study at Harare Central Hospital (CRU) was sought from the hospital administrative offices (Appendix F:). Other ethical considerations applied to this study are outlined below.

3.8.2 Autonomy

Mothers' whose children had been diagnosed with HIV-related NDDs were the primary sources of data and thus it was important to ensure they were treated as autonomous agents. Informed consent was sought from each mother. The informed consent letter included an introductory information letter attached, which was translated into Shona, the first language of the mothers. The informed consent letter clearly outlined the purpose of study and the terms for participation in the study. The letter was read and explained to those mothers who had difficulty reading or understanding the letter. This allowed the mother to make an informed choice as to whether or not to consent to participate in the study. The researcher took time to explain to the mothers that participation in this study was on voluntary basis and their choice not to participate did not affect their access to other services. Although the researcher had met some of the mothers during the workshop, it was emphasised to the mothers that choosing to participate in the study had nothing to do with their previous encounters and will not affect their further treatment at CRU. The researcher also emphasised that the mothers were free to withdraw from the study any time they wished, without any threats or obligation to explain their decision to withdraw. During the research process the researcher was available to answer to any questions related to the research that the mothers had.

3.8.3 Confidentiality

To maintain confidentiality, no original names were recorded, and data was numerically and alphabetically coded. During data collection the researcher collaborated with the mothers to assign pseudonyms to be used in the final write up as a way of identifying with individual experiences of each of the mothers. Only the researcher had access to the collected raw data and this was kept in a safe locker for privacy purposes. Participants were informed how the data would be recorded, stored and processed and that the raw data would be destroyed 18 months after the submission of the thesis to maintain confidentiality.

3.8.4 Beneficence

The study provided a platform for mothers to express and share their life experiences of caring for their child and every effort was made by the researcher to maintain respect and good judgment towards the mothers. Throughout the conversations, questions were carefully structured and presented and mothers were supported to share their experiences. In cases where the researcher felt that the mothers would benefit from other services, such as counseling, referral would be made. However, no mother was referred for such services. Participation in this study was on voluntary basis, thus, mothers were not paid for participation in the study. However refreshments and transport monies were provided to the participants during the study.

3.8.5 Risks and Discomforts

Upon sharing the intimate details of caring for a child with HIV, mothers' may have felt distressed and uncomfortable when asked about some of the topics under discussion. Mothers' were free not to respond and were not forced to give a reason for doing so, if they felt uncomfortable to answer. Provision for further counselling and support services were made for the mother's at the CRU clinic, however none used this facility.

3.9 Conclusion

In summary, a qualitative design has been used to find out the lived experiences of caring for a child with HIV related NDDs from their biological mothers. Phenomenological conversations with mothers managed to generate data. The researcher went through a rigorous iterative process of data analysis, with audit trail to come up with themes that describe the mothers' experience. Principles of scientific rigour and ethical considerations were noted throughout the study. The following chapter presents the findings.

Chapter 4. FINDINGS

4.1 Introduction

This chapter presents the findings of this study. The findings describe the lived experience of caring for a child with HIV-related NDD. The mothers' and researcher's reflections of the setting and context were incorporated into the findings to give a richer description of the caring experience. The findings consist of three themes and sub-themes as indicated in Table 3-1.

Table 4-1: Themes and sub-themes

Theme	Sub-themes
Resilient Acceptance 'Ndozvazviri'	Nothing I can change; you just have to accept it; God's case: no appeal.
Caring for My Child, is too much to entrust to another	A difficult and demanding caring role; Fearing the extension of stigma; I must do it, I caused it; Meeting cultural expectations.
Rekindled hope for the future	Celebrating the survival of the child; Excited by progress; Comforted by others; Privilege of caring.

4.2 Theme One: "Resilient Acceptance (Ndozvazviri)"

The first theme speaks to how each mother came to terms with having to care for a child with HIV-related NDD. Mothers experienced multiple negative impacts – firstly through becoming aware of their own HIV status; then the status of the child; followed soon thereafter by a growing realisation that their child was not developing typically because of an HIV-related NDD. Mothers accepted their situation with resilience: this was something that had happened, they could not change it, so they would need to accept it and move on. The theme 'Ndozvazviri'

and the two other sub-themes: ‘Nothing I can change, you just have to accept it’; and ‘God’s case: no appeal’ captures their resilient acceptance of their situations.

Sub-theme: Nothing I can change; you just have to accept it”

By and large the mothers experienced a difficult entry into coming to know about and accept the HIV status of their child. Mothers only found out about their own status and that of their child when they went to the hospital to register their pregnancy or after frequent illnesses of their child. In Zimbabwe expectant mothers are encouraged to undergo the HIV test as a screening method under the Prevention of Mother to Child Transmission (PMTCT) programme. This is normally done at 12 weeks of pregnancy, coinciding with the time mothers’ register their pregnancies at clinics or hospitals.

It is at this point of registering the birth of her child that Zivai learned about her status.

“When I was pregnant, I went to the clinic and that same day I got tested. I was three months pregnant and I received my results, I was HIV-positive. I was worried. I did not know what to do. I felt helpless. They talked to me and gave me a pill which I was to take the day I would start to have labour pains.

The intent of the PMTCT was not always met because often difficulties with the health care system resulted in mothers not being able to access the needed medication – as was the case with Zivai.

“They also said that I should collect another set of pills when I am seven months pregnant. I went back at seven months and I asked for the pills and I was told that the people who distribute the pills were not around. I came back next month and they said the pills were out of stock. (Sadly) Unfortunately I could not get the pills until I finally gave birth to my child.”

Although, Zivai was HIV-positive according to Zimbabwean PMTCT guidelines she was not eligible to be started on ARVs, as her CD4 count levels were still high (above 350 cells/mm³) – instead she was initiated onto the PMTCT ARV prophylaxis programme. She was given a single dose of Navirapine during labour, the minimum regimen given to mothers enrolled in the PMTCT programme. Zivai was to collect another set of medication in the last trimester of her pregnancy which she was supposed to give to the baby from birth up to six weeks. Unfortunately, when she went to collect the medication, the health personnel responsible for distributing drugs were not present and, on another occasion when she went to the clinic, the drugs were out of stock. Despite all the efforts to get the prophylaxis to prevent mother to child

transmission, her child became infected with HIV. Zivai felt betrayed by the health system and had this to say:

“I have no kind words for the health people, especially those who give medication. Like in my situation, what hurts me a lot is that I went to register my pregnancy in time but up to the time I gave birth, I was not given the pills. I could not have passed the virus to the child.”

Tinashe knew already her HIV-positive status, but her pregnancy came unplanned.

“There is nothing I can change! His pregnancy came without being planned. I thought I was gaining weight until my husband advised me to go to the clinic. I went there and they did a pregnancy test and they said I was pregnant. But I had to go for scan to see how old the pregnancy was. The reports from scan showed that I was three months old. I walked away from that place and I said to myself whatever...”

The word ‘whatever’ here is a close translation of the Shona phrase ‘chero zvazvaita’ which portrays a sense of despair and confusion. It describes the essence of Tinashe’s helplessness, of not knowing how to handle this situation, or what to do.

In all the cases, the whole experience of having a child with HIV-related NDD was never imagined or thought of. Mothers received the news of their status and that of their children with shock and disbelief. In trying to gain an understanding of the mothers’ experiences of knowing their HIV status and that of the child, the researcher inquired further to acquire a deeper understanding of their experiences on coming to learn about the child’s NDD. Their responses resounded as follows:

“I was so devastated...I was just a worrying mother.” (Zivai)

“I was so devastated; such issues are worrisome in life.” (Kudzi)

Although mothers shared their traumatic experiences, the researcher was surprised to note that they seemed to be coping and managing well. This stimulated the researcher’s interest in finding out more about how these mothers were coping with caring for a child with HIV-related NDD. Mothers reported that they had already realised their child had HIV/AIDS and that this was not going to change, hence their need to accept their situations and move on with life. Their resilience, that is, their ability to accept, adapt and respond to these many onslaughts was evident.

“I did not panic, because already I knew my child was HIV-positive and anything could happen. I just told myself that this is the way it just supposed to be (Zvazviri ndozvazviri).” (Tinashe)

“It was difficult for me to accept it. What else can you do? But you just have to accept it.” (Nomsa)

“There is nothing I can change...ndozvazviri...just have to accept it.” (Zivai)

The term ‘ndozvazviri’ is widely used in the Shona language. It signifies a very difficult situation that one encounters and has no power to change. Thus, the individual has to accept the situation as it is, as nothing can be done to change it. The mothers actively accepted their role as mother and carer demonstrating resilience in the face of the challenges.

“That is the way it is, I am the mother and I have to take care of my child.” (Nomsa)

“At times it affects me as I think a lot that why my child is in this condition, but I try to accept it.” (Zivai)

“I just tell myself ndozvazviri (thus the way it is) and I should accept it.” (Tinashe)

Acceptance in a way seemed to help mothers to cope with their situations better and enabled them to carry on with the caregiving occupation despite it being an occupation infiltrated by burdensome tasks. By accepting the condition of her child, Kudzi was no longer affected by what people said behind her back.

“But for me I have accepted it so I am not moved by people.” (Kudzi)

Zivai mentions how she has restructured her daily occupations so as to accommodate her child.

As for me, I have accepted it and so at times I do my work when he is asleep.” (Zivai)

Sub-theme: God’s Case: No appeal

A regard for God as a supernatural being was evident in the experiences of the mothers in this study. All the mothers who participated in this study were Christian. Their belief in God contributed to their acceptance of the condition of the child and their caring role. Mothers believed that whatever God would have done was final and no one had power to change it. Having a child with HIV-related NDD was in accordance with God’s plan and the mothers felt this was reason enough to accept their situation as it is.

“God planned it that way, that on your third child it shall be like this.” (Tinashe)

“There is no one who applies for a disabled child or for a normal child. It just happens; God just gives, so you cannot blame yourself why it happened but just to accept it.” (Zivai)

When Tinashe found out about the status of her child, her experience of being in this role was that she would undertake it with the guidance of God as highlighted in the quote below:

“Whatever God, you know what will happen next.”

In one case Nomsa who, after spending 12 years trying to have a baby, eventually gave birth to a child who developed an HIV-related neurodevelopmental disorder, had this to say:

“I used to cry that why was I given one child, should I stay with only one. If only God was to see and bless me with another child and it happened.”

And because she believed that God had done it to her, Nomsa felt that she had no control over it but had to be happy with having a child with HIV-related NDD. Asked how she felt about having a child with NDD, Nomsa replied saying:

“Aaah ...am happy with that, I have to be, God gave, to whom could it had been done to.”

Mothers also held the belief that a child is a blessing from God. Because the mothers have been blessed with a child, no matter his/her condition, they could not complain or reject a blessing from God. Mothers highlighted that having a child no matter his condition is better than not even having one, and thus they are grateful in their situation.

“There are others who wish to have children but they don’t have. I greatly appreciate that at least I have him although he has problems but I have him.” (Nomsa)

“I think there are some women who do not have that kind of privilege of being a mother and some do not even have a child even a sick one. Some do wish to have one, so I really appreciate what I have.” (Memory)

Mothers acknowledged that taking care of a child with HIV-related NDD was difficult, yet they drew their strength and energy from spirituality. God was defined as a source of inspiration and comfort in times when it is very difficult, usually during the illness of the child and in cases when hope is almost lost. In some difficult situations mothers narrated how they would ask for God’s intervention; which no man could change or go against.

“She got admitted to hospital and doctor said an operation has to be done because her intestines are not functioning very well. I prayed to God. I was praying every day and God heard me.” (Tinashe)

Some mothers even attribute the progress and improvements noted on the child to the power of God.

“Even people who saw him that time if they see him now they will be amazed that he is still alive, only God takes control.” (Tinashe)

The spiritual being (God) is believed to be the source of answers and the mothers depended on him in desperate situations. For example when the child was ill, hospitalised or maybe facing surgery, the mothers would look to God for inspiration.

“God will be the way, He will give answers.” (Zivai)

“It is difficult. You just say I don’t know what will happen next, especially when he gets fits, you just need God to guide you.” (Memory)

A relationship with God meant that the mother had a personal connection with the one in control of the whole universe – ‘The One’ whose decisions are final and no man could go against. The personal connection with the superior being brought comfort, hope and strength to continue with the occupation of caring for a child with HIV-related NDD.

Conclusion

The experience of getting to know about their HIV status, as well as the NDD condition of the child, was difficult for the mothers and there was a feeling of ‘ndozvazviri’ (That is the way it is). Mothers had accepted their situation – one of having a child with HIV-related NDD. The belief in God as a spiritual being and culture played a role in guiding mothers to resilient acceptance.

4.3 Theme Two: “Caring for My Child is too much to entrust to another”

The second theme highlights how the mothers experienced their caring role as complex and multi-layered, making it an occupation that could not be easily entrusted to other person/s, even when those persons were available and willing to assist them with caring for their child. The four sub-themes: ‘A difficult and demanding caring role’; Fearing the extension of stigma; ‘I

must do this, I caused it'; and 'Meeting cultural expectations' capture the mothers' experience of caring for their child with HIV and NDD as being too much to entrust to another.

Sub-theme: A difficult and demanding caring role

The double-barrelled condition of the child being HIV-positive, as well having a NDD, resulted in the mothers experiencing caring as a role consisting of all-consuming, difficult and demanding tasks.

"It is very tiresome to take care of such a child with his condition; there is a lot to do for him." (Nomsa)

"It is very hard and difficult in the sense that he cannot sit alone, so he is in a situation that either he is on my back or in my hands (most of the time)." (Nomsa)

In particular, the physical limitations of the children and their limited independence in movement, self-care and play resulted in the child's prolonged dependence on their mothers.

"My child cannot do most of the things alone (and I have to do them for him)." (Memory)

"By the time he was at the stage of sitting, he got seriously ill, his weight extremely deteriorated and he became like a new-born baby. He later regained his weight but he does his things slowly, he started crawling at 10 months and up to date he cannot stand, so I have to do most of the things for him." (Zivai)

In Zivai's case, her child's limited mobility made caring for him a difficult role for her to entrust to another person.

"The most difficult part for me is that my child cannot walk. So it is difficult for me to leave him with anyone else while that person has other things to do apart from caring for the child. At times my child wants to follow others (children) but he can't and he needs someone to hold his hand so that he can walk." (Zivai)

While dependence on mothers is a natural part of being a child, the mothers spoke of how the caring role for the child with NDDs was different from that of their other children because of their increased levels of dependence on their mothers for a wider array of activities than the other siblings.

“Caring for him is different from other children, it is much more demanding because my child cannot do most of the things alone like other four year olds whom you can send to go and fetch water and they go.” (Tinashe)

“She (his sister) could go to the toilet but he (the child) cannot. He needs me all the time.” (Zivai)

Mothers also expressed how much they felt different emotions towards the child with NDD than his/her siblings which were mainly driven by their child's dependence on them for care.

“I love them both, but I am over protective of the younger one (the one with NDD). He is more at my heart. This is because he is sickly and is not able to do a lot of things by himself.” (Memory)

“At least my older children can do most things for themselves, they are grown up and at times I even forget them, I will be just giving my attention to him (Child with NDD).” (Tinashe)

The several demands for caring a child with NDD have also had an impact on the health of the mothers, more so, because most of the mothers themselves who may have been ill because of HIV.

“My back was painful because of carrying him, he was overweight. Even up to now it's still painful, but I still have to carry him, because that is the only way to move from one point to the other.” (Memory)

“I once had headache, I think I it's because I will be thinking too much. I was not able to do anything that is the only time I called my sister to help with the kids.” (Tinashe)

Children with HIV-related NDDs included in this study were on antiretroviral therapy and mothers had a good appreciation of medication adherence and scheduling. The strict routines of administering their child's medication however contributed to the demanding nature of the caring role.

“It is difficult because what he is supposed to eat should be taken on time which differs from other children who do not have a strict timetable.” (Kudzi)

“She has to take her pills every day and also the type of food she eats is different from others, so it is difficult.” (Zivai)

These strict routines and the responsibility linked to giving medication resulted in the mothers feeling reluctant to share the care of their child with others.

“It is hard because you cannot get someone whom you can trust to care for your child because he has a timetable for taking pills and for taking his food.” (Nomsa)

Some of the mothers spoke of situations when family members who had volunteered to look after the child had failed to follow the timetable and guidelines of administering the medication. These past experiences impacted further on their unwillingness to entrust the care of their child to another person.

“Last time he went to his uncle’s place and he went with his medication for three days, he came back with another pair of pills which meant that he either skipped taking his medication or they were giving him a wrong dose. I tried to ask them (why this happened) and they did not understand. So you see it is just difficult to go anyway leaving him with somebody else.” (Memory)

Their past experiences of their child’s ill health and significant health improvements since starting antiretroviral therapy contributed to the value mothers placed on giving the child medication on time.

“But I can safely say ever since he was started on this medication, I do not have any problems with him. He used to be ever sick, being in and out of the hospital but now it has changed. The pills are doing well on him, and thus why I am strict on his medication.” (Zivai)

Memory valued giving her children medication to the extent that she vowed to stop all other duties to ensure she adhered to the timetable for medication and food for the children at the expense of other occupations.

“Giving them (her children) medication is the most important thing to me and making sure that I keep up with the timetable for medication in the morning and the evening. I can stop all other duties, just to make sure I give my sons their medication because their life depends on this medication.” (Memory)

Caring was as consuming role that drew time away from other occupations was highlighted by Zivai who narrated how caregiving for the child, often made her not to finish her duties.

“At times its quite frustrating, for example when performing some household chores and he (the child) would be playing on your workstation, and at times he needs your assistance and at times you are just following him checking on how he is doing and that eats in to your time and at the end of the day you don’t finish your duties.” (Zivai)

Caring for a child with NDD is an all-consuming role that left mother’s daily occupations centred on the child. Attending social functions was difficult as mothers had no one else to

leave their child with. Kudzi said that she no longer attended funerals where she has to sleep over. She preferred going out during the morning, after she has given medication to her child, and returning home around 6 pm so she would be in time to give her medication.

“Haa funerals where I need to sleep over, I no longer attend. At present, I don’t want to lie; I have not gone to any. I may go if it’s near so that I go in the morning, spend the day there up to around 6 pm and I go back home knowing that I have to give my child her medication in time, at 7 pm sharp.” (Kudzi)

Memory had this to say:

“Like at church functions, at times we do church baby welcomes and you have to attend without children, so I can’t attend such functions.”

Attending social functions gave mothers a sense of belonging and a reconfirmation that they are still part of that community identity.

Mothers viewed occupations that involved meeting and interacting with other women to be important to them because it gave them a sense of belonging and companionship.

“One thing that I enjoy is socialising with other women, just sitting around and talking stories as women make me happy.” (Nomsa)

However their caring role could not allow them time and space to be with other women.

“What I would like doing but I cannot because of this child, is going out with other women especially parties, to relief stress. I cannot go out with her and I have no one to leave my baby with.” (Kudzi)

When engaging with other women they felt they could talk and interact in a general manner while being cautious about the risk sharing or disclosing their personal status.

“When I am with my friends, I join in the discussions and even talk about HIV but I do not talk about my personal stuff. No one knows my situation.” (Tinashe)

Most mothers also expressed how they wanted to go to work so that they could contribute to the financial upkeep of the family. However, because they felt that there was no one reliable who could they leave their child with, most of them could not go to work. The mothers’ situations of unemployment was also precipitated by the high unemployment rates experienced in the country, making it difficult to find formal employment for ordinary people – and worse

still for the mothers who would need flexible working hours to attend to the needs of their children.

“Working?!! We wish to work but if you look at the problem that you have, it does not allow you to leave the child with anyone else, because you create another problem to the child because you leave the child with somebody without care and the child cannot walk, can’t even feed himself so you will see that it is hard ...just working on its own....you would love to be employed but!” (Nomsa)

“What is important for me is to get a job but I cannot...because I do not have anyone to leave my child with.” (Kudzi)

The economic environment experienced in Zimbabwe has resulted in trading as a dominant entrepreneurial business for women. Many women in Zimbabwe are involved in trading of second-hand clothes; fruits and vegetables and many cross the borders to neighbouring countries to buy a variety of goods that they would be able to sell at a profit back in their own country. Mothers highlighted how buying and selling would be an alternative for them, but they still faced difficulties in sustaining it.

“I used to go to South Africa to buy some stuff but it’s no longer possible, because I cannot leave my child with anyone else who cannot monitor her medication because she has to get her medication on time so you need to be home always.” (Kudzi)

“There are things I feel like doing, such as going out there to look for things that I can buy in bulk and sell. But deep down in my heart I feel it’s not proper. What if I go and spent days there like what I see other women doing. I don’t know, (sadly) maybe I may go and my son gets ill whilst I am away. What will I do? I would want to work but I can’t.” (Nodding her head sideways) (Memory)

Zivai, who is in the business of buying and selling of beef, said that she either leaves the child with the husband or goes to the market with the child on her back. However she narrated how her business is affected by the all-consuming caring role.

“What I am doing is the selling of meat (beef and chicken cuts). The profits are low and I cannot make big orders because of the condition of the child. I may be called to the clinic any day or most of the profits are spent on the needs of the child.”

In the Shona culture, where the spirit of ‘Ubuntu’ exists, relatives and friends would offer to relieve a mother of her caring role. These mothers were reluctant to transfer care of their child because of their anxieties that the complex nature of their child’s care requirements could not be met by others.

"I don't feel safe to give him to someone to take care of him, like 'gogo' (grandmother) or the aunties. There are some who come wanting to go with the child, but because of his situation I just tell them that he is still young." (Nomsa)

"Haa no, where ever I am, thus were my child will be. I cannot leave my child with anyone else. (Nodding her head sideways) no one will be able to take care of the child." (Kudzi)

In Tinashe's case, her perception of caring for the child with HIV-related NDD as too much to entrust to another was supported by her husband. She mentions that the caring responsibility for their son with HIV-related NDD could not be shared even with a maid (domestic worker).

"...most of the duties that need to be done for my child I need to do it myself, even my husband said if I am to get a maid that maid should be for the other kids and I be the maid of my child, because I understand the needs of the child better because I am the mother."

There were also situations when the mother would be willing to share the caring role with other relatives but the context of where some of the relatives stayed and the demands of their own daily occupations made it difficult for them to provide support to the mothers. This was especially so in the rural areas, where the caregiver would need to fetch firewood and water from a distance, as well as plough the fields. Kudzi gave an example to illustrate why even her own mother cannot take care of her child when it comes to medication issues.

"Yes, for instances if you have given your mother the child to take care, and she stays in the rural areas and it's time to plough the fields. Her fields are a distance away and she has to go to the fields at 5 am and work there until maybe 10 am. While my child should be given tablets at 7 am, how can she balance the two? So it's difficult for other people to take care of children with such conditions."

Sub-theme: Fearing the extension of the Stigma

"In my community, no one knows." (Tinashe)

Mothers of children with HIV-related NDD were conscious of the prevailing stigma as was evident by their reluctance to relinquish their caregiving role for fear that this might force them to disclose both their own HIV status and that of their child to their relatives, friends and the community. Sharing the burden of caregiving with others risked disclosure of the HIV status of the child. Disclosing that the child was HIV-positive meant that there was a higher chance that the community would assume that the child could have got the virus from the mother. Avoiding stigma by not disclosing the status of child thus served as a way to protect both the

child and the mother. Mothers felt it was better to maintain secrecy about the condition of their child and undertake caregiving as their sole responsibility, rather than risk stigma.

“To tell them that my child is...no! no! no! I can’t...I am not afraid of them asking me to divorce my husband but it’s about my child, they will stigmatise her.” (Zivai)

“I did not tell someone...as with my relatives no relative of mine knows the situation; I haven’t told any especially when it comes to my own relatives from my side. I avoid telling them because I had a sister who was diagnosed to be HIV. And they stigmatised her, so you see avoiding such people is the best. Even up to now I haven’t told my mother about my condition, even when I visit my sisters place I just lock myself in the spare room and give my child his medication or use the toilet so that people do not see me. I will be just avoiding being stigmatised.”(Kudzi)

The narration of Kudzi’s experience speaks to how even family members cannot be entrusted with sharing her burden.

Mothers explained how they have witnessed, at family gatherings, people interacting with HIV-positive people in a discriminatory manner and some have even said harsh words to them.

“Like when you have told people his condition, so you will see how they treat or play with him, and when he gets sick they do not take it seriously that he is ill, they don’t value it.” (Memory)

Because of the fear of stigma, some mothers had anxiety about how to disclose status to their infected children and to their other children (siblings of the infected child). They were not sure how the children would receive and act on this news.

“That is one issue that torments me because you would say as she is growing up she will reach a stage that she will know that she is positive and now she wants to know how it happened...how I will tell her?” (Zivai)

“When he grows up, how he is going to accept it, how is he going to tell others...his siblings! I haven’t told them, it’s painful! But I will just do it.” (Tinashe)

Mothers considered disclosing their status, and that of their children, would make them vulnerable to stigma from family, friends and the community. Even at church where the spirit of sharing and helping each other is most likely to prevail, these mothers felt that they could not share their story with other church members.

“The church is just the same as in the location (suburb), like at church it depends if pastor’s wife can keep a secret because you can tell her and she discloses to people.” (Kudzi)

“At church, no they don’t take it that way. If mother apostle does not take my child, then there is no one to hold him. I don’t know why they refuse to hold my child, when you look at him he is totally different from children with cerebral palsy. He is always smart. I don’t know.” (Tinashe)

The picture of a child with cerebral palsy that Tinashe had was that of a child with evident physical impairments, such as drooling, uncoordinated movements of limbs and always in a wheelchair. Although her child had delayed developmental milestones, the fact that he was not in a wheelchair made her think that people would accept him. To her dismay other church members would not even hold her child. In her sentiments, Tinashe also voiced the thought that those children with disabilities, especially those with physical impairments, are likely to be stigmatised in the community.

Sub-theme: I must do it; I caused it

Feelings of guilt and self-blame further increased the mothers’ feelings that they must undertake the caring roles because they were responsible for having infected their children with HIV and a NDD.

“Just thinking that when my nipples cracked and the blood went into him, I felt so bad. I gave my child what he did not deserve! If only it was on me alone.” (Tinashe)

“I would feel a lot of pain (Crying) I would look at her and say. It’s not her fault. She did nothing wrong but we did it...as parents.” (Kudzi)

“Should I say I did it, No I can’t!!” (Zivai)

There were also situations when self-blame was emphasised by relatives. Memory reported that some relatives blamed them for contracting the HIV virus and inflicting it on the child.

“My father in law, he was blaming me saying I was the one who caused it.”

To counter this sense of guilt and shame, mothers took responsibility of their children, to cover up for the pain believed to have been inflicted on the child.

“I feel my child has suffered enough pain which he did not deserve and I want No more pain for the child, she has had enough.” (Tinashe)

“I will do everything that I can for my child, I don’t want to hear him crying because the pain he went through especially when he was in the hospital is just but enough.” (Kudzi)

Sub-theme: Meeting cultural expectations

The significant role culture and its associated spiritual beliefs played in shaping the experience of caregiving for mothers cannot be underestimated. These factors set the expectations of what mothers can and cannot do. Mothers who participated in this study shared the Shona culture, and this culture gives the responsibility of caring for others, especially children, to the mothers. Culture played a role in positioning women as the custodians of children and the mothers have to be answerable for health issues of the child especially medication. Thus, mothers from this study undertook caregiving as an act of meeting cultural expectations.

“Women are supposed to carry the burden.” (Tinashe)

“It is hard because as the mother. I am supposed to make sure that the kids have taken their medication.” (Memory)

According to the Shona culture, sharing the caring role is widely accepted and children can go and stay with a relative for a while and later come back home. However, entrusting someone with the full caring responsibilities held a different meaning for the mothers included in this study. In these cases, being unable to care for one’s own child would mean failure on the part of the parents and risk being stripped of their own dignity and status in the community. Thus, mothers endured the difficulties in caring to meet the cultural expectations.

“It is not easy but I am the mother. I have to do it.” (Nomsa)

The culture also defines the man to be the bread winner for the family. Husbands are seen to be being supportive of the caring role if they are financially able to provide for the family.

“...if you tell him what the child wants he does exactly like that, for instance we told about having a chair for the child. I told my husband and he bought the chair. So whatever the child wants he provides; he is very supportive.” (Tinashe)

“Yes in our culture it is the mother’s role to take care of the children while the fathers go out there to look for money for family upkeep.” (Zivai)

Memory also points out how different the care of men is from that of women, in respect of her culture.

“The care of men is hidden. He is able to show love for his son but not care like cooking for him or any other duties. Especially taking him to the clinic you need to ask him to accompany you, and if he agrees then you go together.”

The care provided by the biological mother is unique in its way and is shaped by culture and spirituality. Mothers highlighted the qualities in the mother that makes them to provide a unique type of caregiving.

“You can have a sister, you can have a maid but they don’t have that love as that of the mother.” (Tinashe)

“The pain I got during labour, gives me strength that no one has to take care of my child.” (Nomsa)

Although mothers showed respect for their culture and the need to meet its expectations the issue of caring, as a responsibility for the mother alone, was difficult for them. Memory critiques this part of cultural belief and had this to say:

“People should not look forward to the wife alone to do everything alone but to help each other.”

The position of women in society, makes them to the ones available most of the time to attend to counselling and workshops on HIV/AIDs. Some of the mothers felt that because of their attendance at the workshops, they were the ones most knowledgeable to take care of their child.

“Attending workshops at CRU was very helpful, it enlightened me a lot, so I view myself most knowledgeable of taking care of him than anybody else.” (Zivai)

“We have learnt what HIV/AIDS is all about, more than most people.” (Kudzi)

Culture has set expectations for mothers in performing the caring role. Mothers have been culturally made to view themselves as the ones capable of caring for the children. This is even more important when caring for children with HIV-related NDDs where the caregiving demands are viewed as too much to entrust to another.

Conclusion

Caring for a child with HIV-related NDD is unique in the challenges it presents. These challenges draw extensive time away from the mothers’ other occupations. Challenges involved in caring were exacerbated by the limited available and possible family support and the mothers’ reluctance to access support, even when it was available. The relinquishment of

or sharing of responsibility also placed them at great risk of their diagnosis being discovered and consequently being stigmatised.

4.4 Theme Three: “Rekindled hope for the future”

Although the mothers concurred that the experience of caring for a child with HIV-related neurodevelopmental disorder/s was difficult and challenging, they also reported events or situations that rekindled their hope and brought lighter moments to their caregiving occupation. These included instances where mothers, while caring for and playing with their children, noted improvements in the developmental milestones and overall health of the child. The theme of ‘Rekindled hope for a future’ and the sub-themes: ‘Celebrating the survival of the child’; ‘Excited by progress’; ‘Comforted by others’ and ‘the privilege of caring’, unpacks the positive and gratifying aspects of the mothers’ experiences of the caregiving occupation.

Sub theme: “Celebrating the survival of the child”

Noting the progress of the child and the positive changes happening in the child brought a sense of joy, hope and relief to the mothers. This applied even more when the mothers had experienced situations where they had been told their child would not be able to do anything in life or that the child’s life expectancy would not be long. As the child showed progress, emotions of grief, sorrow and despair were complemented with hope for the future.

“I am just happy with the improvements I am noticing. Yes I feel so happy because you know if you are in closed doors and you hear doctors saying this and that and on top of that, he(child) got tested and found to be HIV-positive. (I)...would say now he is an invalid cabbage, he won’t do anything in life. So now with the improvements I feel so happy.” (Memory)

Caring for a child who has been defined as having nothing to contribute to life and who would die at any time was difficult for the mothers. Tinashe narrated how, at one point when her child was very ill, she thought at any point the child was going to die. It was a difficult situation for her, as she had lost hope and did not know what to do.

“At one point I thought she was going to die...I had lost hope...but now I’m satisfied with her progress.”

Some of the mothers had heard of various myths and beliefs that a child with HIV and disability had a short life expectancy. These beliefs worried the mothers and made them uncertain of the

future of their children. In one of the interviews, Nomsa mentioned that she had been told that children infected with HIV die before the age of seven years, but when she had come to the CRU and saw other children infected with HIV who were older than seven years, she was relieved. She felt better as she learnt of the progress other children with HIV, who were achieving their developmental milestones and maintaining good general health.

“I once heard people saying that a child with HIV do not survive up to seven years of age. And I was afraid and worried, thinking that she may die anytime soon. But when I came to CRU, it was unbelievable seeing some children like her who are ten years old, and the sisters assured me, I know my child is not going to die anytime soon.” (Nomsa)

Memory also narrated how she used to think that her child was going to die when he had seizures (fits).

“I did my own diagnosis and was afraid. I used to think that if he gets fits he may die. But it has reduced since last year August. It’s now better and I have peace.”

Progress in the child seemed to wipe away the death sentence that had been ascribed to the child and assuaged the fears of the mothers. Improvements in the general health of the child rekindled hope in the mothers. Vast reductions in episodes of severe illness, as well as fewer hospital admissions, were among the factors that added to their happiness.

“My child has not been critically ill for the past one year and had not been admitted in hospital. Which is good for me, I don’t have problems right now. All is normal.” (Tinashe)

Sub theme: “Excited by progress”

Children who had been ill and started on ART therapy were recovering and, with time, were showing health improvements and progress in their development. This contributed further to the mothers’ hope of continued recovery.

“He can now walk and ever since he was started on medication he has never deteriorated on his weight.” (Memory)

Progress of the child was described in terms of general health, increase in body weight and attainment of developmental milestones. Progress in terms of developmental milestones was a significant motivator for the mothers as they linked the progress displayed here with reduced disability, and a lessening of the burdensome caregiving demands. Some children had regressed

in terms of developmental milestones during episodes of illness. Noticing progress on the child re-kindled hope and brought excitement to the mother. Mothers could not hide their happiness and joy as they shared stories about the positive changes in their children.

“These days I am celebrating the fact that my child is able to say a word mama...huya (mom come) what an improvement!” (Memory)

“All he does just excites me, he changes every day. I know my child will walk one day, with the progress I am seeing. I know he is going to improve more.” (Tinashe)

“I am excited! At first he could not do anything but now he is able to do this (bringing hands together) so now he can hold things.” (Nomsa)

Their child's improved ability to initiate and do activities alone meant a lot to the mothers especially when a child had not been able to do anything before. Noticing the child achieving a new ‘doing’ – no matter how big or small, good or bad – these mothers cherished every ‘doing’ of their child with happiness. These small tasks included the child bringing two hands together, eating alone, playing, saying a word or even choosing what they wanted to wear.

“At the moment, he is able to select things that he likes even on television, he can suggest what to see or clothes he is able to choose what to wear and that alone make me happy.” (Zivai)

The experience of seeing the child show a sense of autonomy through being wilful (referred to below as naughty) built on the mothers’ hopes of their child developing into a human being with the ability to exercise choice.

“He is naughty! (Laughing) you can see that this person has brains and is naughty. He does what he feels like and I am happy with it. If he doesn’t become naughty you definitely want to find out.” (Tinashe)

Mothers were also excited when their child showed increased awareness and cognitive abilities.

“What he does that excites me is when I call his brother, he (the child) also responds, even if you place food in front of him he looks around, looking for his brother so they can eat together.” (Nomsa)

“If he is playing outside and we are just the two of us at home. If there is a visitor or someone who wants to buy something he comes crawling or walking with support of the walls and says ‘Mama diwa’ (‘Mum you are wanted’). (Smiles)...I depend on him. He knows that we sell stuff.” (Zivai)

When mothers viewed the condition of their child in comparison with other children, some mothers saw their children to be in a better position than others. Mothers felt that they had a lesser/better burden than others and were appreciative of what they have.

“If I sit him with others (children) at CRU, I ask myself, why am I here, because he is even much better than others?” (Tinashe)

“What excites me most is that he is no different from any other children even when you put him amongst other kids, you won’t notice the difference but I do because I know his condition. My child looks fine and more than other normal kids and that really excite me.” (Zivai)

Progress in the child also allowed the mothers to do other occupations as well as open new possibilities in life. In situations when the child was severely ill mothers forfeited some of their meaningful occupations, outside of caring, and dedicated all their time to the child. As the child progressed well and caregiving demands lessened, mothers could now do some of the occupations that they previously stopped/abandoned.

“I can say, this year is when I was able to attend a funeral in April, he used to fit a lot and could not take him where there are too many people. It is better these days.” (Memory)

Progress of the child also allowed mothers to start thinking of other ways of looking for a job or participating in income generating activities to help sustain the family.

“I could not look for a job because my child had been very sick, but now he is much better. So at that time you would see that there was no one whom you could leave the baby with. He is now much better, even if I get a job as a maid (Domestic worker) I can do it.” (Memory)

“I think you (directed to researcher) have noticed a difference, compared to those days (during first interview), my child is now better, I can now think of looking for a job, so that I can support my child.” (Kudzi)

Engagement and participation of the child in play was a key factor that brought relief and excitement to the mothers. This could have been attributed to the fact that play, for both children and adults, is identified in the Shona culture as a significant measure of health and wellbeing in children. If a sick child was still able to engage in play, then nature of illness was not viewed as serious. Shona nurses also use play as a yardstick to determine the severity of illness and often nurses ask mothers if the child is playing when they take case histories.

Engagement in play for a child with NDD signified a sense of health and wellbeing, thus, mothers were excited when their children engaged in play.

“What excites me is that my child can play, he enjoys playing even with other children.” (Zivai)

Mothers valued the times and opportunities for engagement and participation in play of the child. It was important for the mothers to set time aside to play with their child. Mothers shared their experiences of engaging in play with their child.

“Normally I go where he is playing, I sit with him, if he is playing house. He would ask ‘Mama do you want sadza (pap)?’. I would reply ‘Yes’, so we sit in such a way that we can share the sadza he would have cooked with mud.” (Zivai)

“He likes soccer a lot, he also like cars so I act as if I am the hooter of his car and this makes him happy. When he hears me making the ‘tu tu tu’ sound of the hooter, he laughs a lot, he likes it.” (Memory)

“I played different things with them, like when we are home and I have time, I sit and play with them. He enjoys playing Amhina (a traditional game). I also play with him using a ball and there is also some drums which we were told to make for them at CRU, so that is what I can play for him. I beat the drum and he nods his head showing he is enjoying it.” (Memory)

At CRU, workshops are presented on play. In these workshops the value of play is emphasised and mothers are encouraged to make traditional low-cost toys for their children. Guidelines to make these toys are provided to the mothers and they are encouraged to incorporate play in the daily physical exercises they do with the child so that the child enjoys exercise time. Play while doing exercises is seen as a means by which the child could be actively encouraged to take part in the exercise programme, as well as learn to enjoy therapy.

“As told at CRU, I also play during the time I will be doing exercises with him and he likes it.” (Zivai)

Progress of the child was also noted when the child was able to engage and play with other children. Two of the mothers reported that they felt happy to watch the child play safely with siblings or other children in the community. Watching their children being included in play with other children brought a sense of happiness and joy to the mothers. This could be linked to the sense of belonging the mothers experienced because their child was doing what other children in the community were doing, despite the disability.

“I was happy to watch my child play with others. He can now safely play with others. You see that he has a lot of potential and it is beginning to show.” (Memory)

“I like watching him play with other children, including his siblings. When he plays with other children, they put him in those small cars where he can sit and he is pushed whilst inside, they play on the keyboard and so forth.” (Tinashe)

The experience of having a child with NDD engage in play meant a lot to the mothers. In situations where the child had physical limitations that affected engagement in play, mothers made an effort to facilitate the child to engage and participate. Toys and the nature and type of play could be adjusted to allow the child to engage in play. At times the mother would position their child in a way that promotes play either alone or with others.

“My child needs support so that he can play, so I sit him in a dish and wrap him around with a blanket for support. I invite other children to come and play with him. I will be watching, just in case he falls.” (Nomsa)

Although the neurodevelopmental delay in these children at times made it difficult for the children to engage in play, the mothers continued to encourage play even if the child had difficulties in responding to their actions. Mothers valued an opportunity for the experience of play for the child, to the extent that, in some cases, the mothers would direct the form of play the child engaged in.

“He also like cars, so I act as if I am the hooter of his car and that makes him happy, when he hears me making the ‘pee pee’ sound of the hooter he laughs a lot, he likes it (Laughing).” (Memory)

“When we are playing with him, we talk stories and all sorts of things, but he does not talk (The child just smiles and giggles in response).” (Nomsa)

The experience of engagement in play with the child or watching your child play either alone or with other children was in itself fulfilling for the mothers.

Sub-theme: “Comforted by others”

Mothers shared how the experience of being surrounded by supportive people and/or meeting with other mothers, whom they identified with as having similar problems, positively impacted on their experience of caregiving. Mothers who stayed with their husbands shared how their caregiving experience had been influenced by their husbands’ companionship and support. Tinashe says that her husband accepted the condition of the baby without difficulty and that made him supportive.

“He has accepted it all! As for accepting the child it did not take him time. We stand together.” (Tinashe)

“I am blessed to be staying with my husband, because some man ran away from home the moment they find out (the condition of the child) for me it’s much better because we are together.” (Zivai)

Some mothers have often interacted and built relationships with fellow church members. This has resulted in them getting assistance and support which, in turn, lessened their burden of care. Support from the church, in a way, instilled hope in the mothers. Memory shares how the church has supported her.

“Also a church relative and a blood relative are different because a church relative understands better, even if you ask for something to go and cook for the children, she will give you rather if you ask neighbours they will go and talk about you. Even when I don’t have bus fare my pastor does assist me.”

The opportunity offered by the Harare Central Hospital’s Children’s Rehabilitation Unit for mothers to meet during programmes and workshops were conveyed as being pivotal in helping mothers to accept their situation. At CRU, treatment of the child is primarily individualistic and is mainly centred on the child. The researcher observed that mothers would be seated in the waiting room, waiting for their turn to see the therapist. It is at this time that mothers would talk and share experiences of caring for their children. They would discuss a variety of issues, counsel each other and share advice. Mothers reported that meeting with others and realising that they are not alone in the journey of caregiving rekindled their hope for a future.

“It gets better as you meet other parents with children who are just like her.” (Nomsa)

CRU holds different workshops for caregivers of children with disabilities. The workshops are also created as a platform for mothers to interact and share their experiences. Some of the workshops are designed in such a way that there are opportunities for mothers to share their experiences, as well as advice how they have overcome their challenges.

“I am encouraged and given hope at the workshops that we attend here at CRU, they are comforting. At times I think a lot and it affects me when I am alone, but when I remember what has been said at the workshop. I comfort myself.” (Nomsa)

“At first before I met others with such problems, it was difficult for me to accept it. But when I saw others, I realised that my problems are far much better than problems of others. Especially here at CRU.” (Kudzi)

Sub-theme: “The privilege of caring”

The discourses surrounding HIV/AIDS in the Shona culture assume that when one contracts HIV, the infection automatically carries a death sentence. Thus, individuals with HIV are viewed as helpless, powerless and awaiting their time to die. Mothers caring for their children with HIV-related NDD have challenged this discourse and managing this caregiving role means a lot in their lives. Mothers expressed that taking care of their children was something very important and meaningful to them and they would want to continue doing it.

“What I value most is caring for my child as well as planning for his future. Like any other child, you would want to be able to take good care of him, see him grow, go to school and have a better life,” (Zivai)

Despite the occupation of caregiving being associated with a lot of challenges, the experience of being able to undertake the occupation means a lot to them. This applies even more when the mothers have managed to fulfil the caregiving roles as evidenced by the progress of the child.

“Because it is just so difficult to take care of such a child in such in such a condition and being able is so important to me.” (Nomsa)

“Just seeing them growing and being identified as the mother of these two I just feel excited.” (Memory)

In comparison to other women, Mothers were also comforted by the fact that at least they had children.

What makes me excited is just having him as there are some out there who do not have children.” (Tinashe)

“At least I have a child; there are some people who do not even have any.” (Kudzi)

Conclusion

Despite the negative moments described by the mothers caring for a child with HIV-related NDDs, they also reported experiencing many positive moments. The positive experiences mainly occurred when mother noticed progress in the child or when playing and interacting with the child. Progress in the child rekindled hope in the mother and it brought a measure of

joy and excitement. Also, instances when the child was able to engage in play and doing the same as the other children were doing, added to the positive experience of the mothers.

Chapter 5. DISCUSSION

5.1 Introduction

The chapter will discuss the findings, drawing on literature presented in Chapter Two to frame a deeper understanding of the lived experience of mothers caring for their child/children with a HIV-related NDD. A transactional perspective (Cutchin *et al.*, 2008; Dickie *et al.*, 2006) will highlight the interplay between the personal attributes and challenges of the mothers and their contexts, as the key determinants shaping their experience of being a mother of a child with a HIV-related NDD. The discussion will also argue for an extended view of the occupation of caring, highlighting the meaning-making processes of the mothers in this study and how they reframed the concepts of caregiver burden and burden of care which have been linked to mothers' caring for children with chronic illness and/or disability. These central points of the discussion argue for a deeper consideration of the nature and type of support occupational therapists can offer to mothers of children with chronic illness and disabilities.

5.2 Guilt, shame and self-blame fostering the complete investment of mothers in their role as caregivers.

For the mothers in this study, the process of coming to know the status and diagnosis of the child was traumatic because some of the mothers did not know their own status and thus had to come to terms with this, in parallel with discovering the status of their child. For the mothers who knew their status prior to the birth of the NDD child, the pregnancies were unplanned. Stages of grief, such as guilt, depression and bargaining outlined by Kubler-Ross (1969) in her book on death and dying, were evident in the phenomenological interviews undertaken with the mothers in this study. Herein they conveyed their traumatic experiences of finding out their diagnosis, that of their child and then the child's diagnosis of the HIV-related NDD. These stages of grief were similar to those experienced by mothers of HIV-positive children featured in a study by D'Auria *et al.* (2006). The stigma and discourses surrounding HIV/AIDS, which view being HIV-positive as a death sentence, added to the stress the mothers experienced.

The diagnosis of the child as HIV-positive implied that the mother could also be HIV-positive and therefore be the one who had infected the child. Mothers expressed feelings of guilt and self-blame for having passed on the HIV virus to their children. Vallido *et al.* (2010) and

Demmer (2011) described also the guilt and self-blame that HIV-positive mothers hold for infecting their children. In this study, the guilt and self-blame of the mothers was compounded by feelings of uncertainty about the progression of the HIV and NDD, their fear of the child's recurrent illness and possible hospitalization of their child.

Being a mother to a child with HIV-related NDD was dominated by "doing for", with the mothers performing most of the daily activities, such as toileting, feeding, and bathing, for the child. Although "doing for" a child is part of the mothering role, mothers in this study conveyed that caring for a child with NDD was more demanding when compared with the care they had to provide for their other children without HIV-related NDD. Nicholl and Begley (2012), in their study of caregiving for children with complex needs in Ireland, also found that mothering was dominated by meeting the physical needs of the child.

Of the caring duties mentioned, what seemed to be most demanding was the strict routines of giving medication and food – which aligns with the findings of a study by Van Graan *et al.*, (2007). This latter study explored community-based care of children with HIV/AIDS in South Africa. In this study, the importance of drug compliance was emphasised at the clinic and at the workshops conducted at the CRU. These educational talks, combined with their past experiences of seeing their child's health improving once the medication was started, enhanced the value mothers placed on ensuring they adhered to the strict routines of giving medication. They structured their daily routines in ways that meant they would often forgo other occupations so that they could adhere to the strict administration routines of the medication. This restructuring of routines to prioritise the needs of the child can be likened to what Larson (2000) described as the mothers' "*...orchestration of occupational engagement...*" in ways that allowed them to meet the needs of their children.

The demanding and consuming nature of caring for a child with HIV-related NDD impacted on the episodes of weakened health of the mothers (many of whom were HIV-positive themselves). Some mothers in this study reported back pain and headaches because of the physical and psychological stresses involved in caring for a child with HIV-related NDD. Reports of pain and strain to the body are indications how of how the mothers overwork themselves and entail that mothers could be victims of occupational injustice, occupational imbalance to be specific. The mothers, however, did not succumb to these stress factors and it was often only a last resort for the mothers to seek help for their own health needs or concerns

because of their complete investment in being available for their child. The prioritisation of the child's needs at the expense of one's own health is a common trend in mothers caring for a child with disabilities (Nelson, 2002). Hejoaka (2009) described how mothers will do their utmost to comply with what they perceive to be a good mother by silencing their problems and prioritising the needs of their child.

What was interesting is that, as opposed to becoming trapped by these feelings, the findings demonstrated how the mothers reacted to their feelings of guilt and self-blame in agentic ways, channelling their time and energy into the role of being a mother. Despite the challenges of caring for, often exacerbated by the contextual factors discussed next, the mothers were completely invested in their role as caregivers of their children with HIV-related NDDs. This argument will be built on and extended further throughout the discussion.

5.3 Contextual factors shaping mother's caregiving experiences

Occupation provides a medium through which humans transact with the environment (Cutchin *et al.*, 2008). Hence, what people do is shaped by the context and, inversely, the context is influenced by the occupations in which people engage (Phelan & Kinsella, 2013). Therefore it is difficult to talk about the caring experience of the mothers outside of the influence of their context/s. In this study the role of being a mother for a child with NDD was shaped by contextual factors that included stigma, culture, spirituality and economy. These factors will be discussed further, in line with the findings from this research.

Stigma

Despite awareness campaigns and strategies to mitigate stigma caused by HIV/AIDS, people with HIV/AIDs still face and experience stigma in Zimbabwe (Daffy, 2005). Therefore the HIV-positive mothers' risked being subjected to stigma if their own HIV status, and that of the child, became known. Mothers in this study conveyed their consciousness and fear of this stigma through their narratives of previous experiences where they had been witness to friends and family being stigmatised as a result of their HIV status. The double risk associated with disclosure was linked to the mothers' fears that disclosing the status of the child also meant the risk of disclosing their own status. Avoiding the stigma by not disclosing the status of child served to protect both the child and the mother.

The threat of stigma extended its impact to affecting mothers' participation in activities outside of the caring role. While the mothers expressed how attending women's gatherings, such as kitchen parties and baby showers, was a means by which their identity of being part of the women's society was revived and reconfirmed, they often declined the invitations to attend these events because of the potential risks the social interactions posed to the exposure of their own and their child's status. They also expressed how, even when present at these gatherings, they felt somewhat disconnected from the other women and the potentially meaningful contributions the women's gatherings could provide. This was because they could not use such gatherings as platforms to share their stories and receive support as this would expose them to the possible judgment by other women present at the gatherings.

Hejoaka's (2009) study of HIV-positive mothers in Burkina Faso highlighted the tensions experienced by mothers when balancing the need to maintain the secrecy surrounding the disease and the openness they would need to show if seeking assistance with child care and other forms of social support. This tension was evident in this study because while mothers had possible avenues of support from friends, family and the church, their past experiences of witnessing the stigma linked to drawing on these sources of support resulted in these mothers preferring to undertake caregiving as their sole responsibility.

Culture

Sherry (2010) described how culture plays a role in shaping what people do and how they experience engagement in meaningful occupations. It was evident that the mothers' experiences of caring for their children were guided by the socio-cultural norms of the Shona culture which dictated the implicit rules and expectations of being a good mother. The Shona culture gives the responsibility of caring for others, especially caring for children, to mothers. Mothers are expected to be the custodians of children; mothers have to be answerable to health issues of the child, especially for administering medication. Mothers, in this study, for the most part agreed that caring for children no matter their condition was a woman's role. Being a woman, as well as having a child with HIV-related NDD, meant that the mother should take up the caring role. Memory, one of the mothers participating in this study criticised the Shona culture for framing the caring role as solely a woman's role. The belief that caregiving was a female role tends to overload the mother because she still has to perform roles other than caregiving. The load is even worse in Zimbabwe, where often mothers have been forced to engage in income-generating business, such as trading, to contribute to the upkeep of the

family. Although the economic situation in Zimbabwe forced mothers to engage in productive work, the culture still expected the same mothers to undertake the primary role of caring for children. The juggling of these two roles, of working and being a carer particularly in the context of caring for a child with HIV-related NDD, may result in the mothers being overwhelmed by their varying task demands.

Spirituality

All the mothers involved in this study were Christian and they believed that God had control over their lives and what He had decided was considered by the mothers to be final. Mothers believed that it was God's plan for them to be the mother of a child with HIV-related NDD. To them a child, no matter his condition, was a blessing from God. Thus, being a mother was a privilege, a sign that they were blessed. Kimani-Murage *et al.*, (2010), in their study on caregivers in South Africa, noted that the spiritual belief that God wanted it to be this way, helped caregivers to cope with their role. The spiritual beliefs (faith) held by the mothers in the current study helped them to resiliently accept and undertake the caring role for the child.

Being a mother of a child with HIV-related NDD was difficult and stressful. Mothers often experienced situations that questioned their motherhood. God was viewed as a source of inspiration, comfort and hope for the future, usually during the illness of the child and in cases when hope was almost lost. A relationship with God meant that the mother had a personal connection with the one in control of the whole universe. That personal connection with the superior being brought comfort, hope and the strength to continue with the occupation of caring for a child with HIV-related NDD. Similar to the study on early responses of HIV-positive mothers to the birth of an HIV-exposed infant by D'Auria, *et al.* (2006), the mothers who participated in this research also prayed and depended on God during stressful moments. Although all the mothers in this study believed in God and attended church, they held varying views of the church as a source of support. In South Africa, Demmer (2011) reported that caregivers attended church but did not get much support from the church. Fear of extending stigma and lack of trust in keeping confidences by church personnel were some of the reasons that mothers would not have shared their stories to obtain support from the church. In this study the mothers' ambivalence toward the church as an entity of support was also evident.

Economy

Being a mother entailed providing for the child materially. In other countries, such as South Africa, mothers receive social grants to take care of their children with disabilities (Kimani-Murage *et al.*, 2010). The situation is different in Zimbabwe where disability grants do not exist. One mother reported that access to financial support from the Social Dimension Fund was difficult. Mothers of children with HIV-related NDD in Zimbabwe had to find their own way of living and coping with the needs of the child. All the mothers involved in the study reported that they valued going to work or being involved in an income-generating business to finance their daily expenses. Moreover the economic environment in Zimbabwe requires that both parents be involved in productive work to achieve a modest lifestyle for themselves and their children.

Being involved in productive work was even more critical for single mothers and those whose husbands were not working. Mothers were caught in between being there for the child and entrusting their caring role to another person, thereby allowing them to go for work – mothers however felt they had no one to whom they could entrust their child and this prevented them going out to work. Also, the opportunity to engage in work is also made difficult by the socio-economic environment in Zimbabwe. The high unemployment rates experienced in the country make it difficult for ordinary people to find formal employment; it is worse still for the mothers who would want flexible working hours to facilitate attending to the needs of their children. Although informal employment in the trading industry and, specifically, the buying and selling business could have been an option, mothers also highlighted the difficulties in undertaking such occupations.

Some of the challenges that mothers faced: included lack of enough capital to start the business, regular interruptions required to attend hospital visits, when child is ill or for reviews. The fact that they had no one to leave the baby with while they went to buy things, for onward sale, was the major factor making it difficult to engage in any informal trading business. Denial of opportunities to engage in productive occupations predisposes mothers to poverty. The risk of poverty conditions worsening for people living with HIV was also noted by Kimani-Murange *et al.* (2010), who highlighted the need for creative and effective income-generating strategies.

Apart from drawing time away from mothers to participate in work, the all-consuming nature of the caring role, makes it difficult for them to engage and participate in meaningful

occupations. The difficulty in entrusting the caring role to others made mothers the full-time care custodians of their children, with caregiving dominating the daily occupations of the mothers. Mothers had little or no time to spare for them to engage in any occupations beyond the caregiving that was personally meaningful to them. As a result, this limited the opportunities for these mothers to engage in any occupation that required her participation without the children. The above highlights how the interplay of both personal and contextual factors, fostered the complete investment of the mothers in the caring role and often distanced them from those other occupations which would ordinarily form part of a mothers' daily life. Despite the difficulty and demanding nature of caregiving, mothers were involved in a meaning-making process which enabled them to reconceptualise a different view of the burden.

5.4 A reconsidered view of caregiver burden

While the above discussion of the findings paints a powerful picture of the caregiver burdens experienced within the group of participant mothers in this study, what also comes strongly to the fore is the meaning-making the mothers ascribed to their role as caregivers for their children with HIV-related NDD. Although the tasks associated with caregiving were burdensome, the mothers were not bowed down by the caregiver burden; instead they responded to the burden with enthusiasm and vigilance, valuing their role as mothers and caregivers, resiliently accepting their responsibility to care for their child, valuing the privilege of being a mother. The theme "Resilient acceptance" captures how the mothers accepted being a mother and caring for the child, placing this role above all else.

Despite the demands of the tasks associated with caring for their children, the mothers were reluctant to share this responsibility. While this could be attributed to the lack of support, fear of stigma, past negative experiences with persons to whom they had entrusted their child, the diligence and responsibility for the care of their child appeared to be more grounded in their beliefs that they were the only ones capable of undertaking that role – because they believed, as the mother of the child, they had the expertise to do so. They placed incredible value on their skill in caring for their child and it was this value that shaped their identity as a mother/caregiver.

This determination was evident, when even in the midst of the stressful and traumatic experiences of coming to terms with the child's diagnosis; mothers were committed to and took

on the complete responsibility for being a good mother to their child. The mothers involved in this study framed what was meant by being a good mother for their child, a role that was pivotal in shaping their identity. Vallido, *et al.* (2010), in their narrative synthesis on mothering disrupted by illness, noted that what constituted the meaning of good mothering varied from one research study to another, depending on the diagnosis of the children and the environment. In this current study, being a good mother did not only mean being there always to protect and provide for the child but also was considered an opportunity to generate meaning in the life of the mother.

Vallido *et al.* (2010) noted that the mothering role is a source of pride and gave women a meaningful identity and a sense of belonging. In the Shona culture, discourses surrounding HIV/AIDS assumes that when one contracts HIV, the disease automatically holds a death sentence. Thus, individuals with HIV are viewed as helpless, powerless and awaiting for their time to die. An opportunity to care for one's own child, no matter the conditions, challenged this discourse and managing this caregiving role brings meaning to their lives. Mothers expressed that taking care of their children was something very important and meaningful to them and they would all want to continue doing it. The value placed on this demanding caregiving occupation sustained their engagement in it. This finding is echoed in a study done by Sungh (2011) in South Africa, where grandmothers, who were caring for children infected with HIV, expressed their willingness to continue with the caring for their loved ones, despite the challenges associated with caregiving.

As captured in the theme “Ndozvazviri”, mothers took on the challenge and accepted their situation and their need to care for their child. Acceptance of the caring role enabled mothers to cope with their situations better. A study by Kimani-Murage *et al.* (2010), had similar findings, where acceptance of the child's HIV status helped the caregivers to cope. Mothers were motivated to and resilient in their care of their child. Resilience in Shona woman, and in Africa at large, is an area that has not been well explored. Lin, Rong and Lee (2013) conducted a concept analysis of caregiver resilience in the context of caring for a child with chronic conditions in China. They defined resilience of a caregiver as “...a process of interaction between the caregiver and the environment in a bid to balance protective factors against risk factors. When placed in an unbalanced stressful situation, a caregiver proactively seeks balance in life by appraising the positive meaning of the event.” (Lin et al., 2013; p. 328). The definition of resilience resounds with the findings of this current study in which mothers

navigated the onslaught of negative contextual and personal factors, shaping themselves with the help of their faith and at times family to adjust and reframe caring burden and draw on the positive aspects of caregiving.

Cutchin *et al.* (2008) described the goal of engagement in occupation as having ‘ends in view’, constantly changing and adapting. As mothers engaged in the caring role, their acceptance of this role was built on by positive experiences within the caregiving role. Mothers reported exciting moments, such as watching the child grow and play, as well as the improvements in the health of the child. Kuo (2011) stated that caregiving situated by habits and context provided a means through which mothers improvised creatively every day to achieve desirable ends. Progress in the child was used as a confirmation of being a good mother. Noting the progress of the child, and the positive changes happening in the child, brought a sense of joy, hope and relief to the mothers. Relief could have been because mother had previously experienced negative situations when the child was severely ill and was not able to do anything. Instances when the child who had been seriously ill recovered brought back a sense of joy to the mothers and assurance that they were doing the right thing.

Mothers valued ‘doing’ in the child. An element of ‘doing’ was noted when child was able to crawl, walk, feed and engage in play. As mentioned by Wilcock (1999), ‘doing’ is a term that has gained popularity in the occupational science and occupational therapy profession and is synonymous with occupation. Mothers echoed the same notion as Wilcock (1999) considering ‘doing’ as a determinant of health and well-being. Mothers valued even the smallest things that the child did. The experience of watching one’s own child exhibit a sense of ‘doing’ and autonomy generated meaning and fulfillment for the mothers. In some instances, the mother would be happy even if the child exhibited willful behaviours. ‘Doing’ meant less dependence on the mother and, as the child was able to engage and participate in more occupations (such as feeding, toileting and play), mothers could be free to do other occupations. There is potential for occupational therapists to continue to build on the meaning of the mothers in their caring role by promoting ‘doing’ in the children with HIV-related NDD.

5.5 Power of Collectives

Although mothers expressed their lack of interest in sharing the caring role, they felt the need to be with others. This is because human beings need each other and it is through relationships

that people develop their full potential (Ramugondo & Kronenberg, 2013). Mothers shared how the experience of being surrounded by supportive people positively impacted on their experience of caregiving. The culture of Ubuntu was evident in the experiences of the mothers. The spirit of Ubuntu denotes that each person is inextricably bound to the whole of humanity and what happens to humanity happens to the group (Sherry, 2010). The human need for others and the power of collectives seemed to play a pivotal role in creating positive experiences and rekindling hope in the mothers. The companionship and support from family members made it easier for mothers to accept their situation. Mothers who stayed with their husbands shared how their caregiving experience had been positively influenced by their husbands' companionship and support. Situations of being with other mothers, who were identified as being in a similar position, were a form of support to them. It made them realise they are not alone.

The focus on the collective occupations is gaining attention in occupational science. Dickie *et al.*, (2006) criticised the individualism approach and highlighted the need to look into the collective nature of occupation. Although mothers in this study undertook caregiving literally as their sole responsibility, through feelings of guilt over their child's illness and fears of extending stigma, caregiving is an occupation that has potential to be jointly adopted by more than one individual. Regarding caregiving as a transactional experience, by moving beyond the individual based understanding to encompass others (Dickie *et al.*, 2006), would yield benefits for both the caregivers and the occupational therapists in building holistic support structures for the mothers.

In the case of caring for a child with HIV-related NDD, it becomes imperative to gain support from family, friends and the community at large. But the mothers in this study reported that they could not share the caring role, not even when family and friends offered help. Mothers said that they can talk about all sorts of stories but not disclose their own HIV status, and that of the child, to other people. In other cases, mothers felt that the context in which some of their relatives stayed made it difficult for them to be entrusted with the caring role. Stigma and guilt contributed to mothers not wanting to share their caregiving role. Kimani-Murage *et al.* (2010) noted that the stigma associated with HIV/AIDS prevented mothers from accessing available support. The challenge that mothers faced was to balance their need for collectiveness and support versus their need to ensure their protection from stigma.

5.6 Conclusion

Despite the demanding and difficult nature of caregiving, mothers involved in this study ascribed different meaning to the caring occupation. In the face of the burden, mothers engaged in a meaning-making process and viewed caring for a child with NDD as fulfilling. Mothers viewed caring as an occupation that they could not share with others and this perception was influenced by both personal and contextual factors. The study reveals the transactions that happen between the mother and the context (environment) in which the occupation of caring for a child with NDD takes place. The motivation and feelings of guilt made mothers invest all their time and energy into caregiving. The role of the context, which included culture, spirituality and the fear of extending stigma, in shaping the experiences of the mothers could not be underestimated and it would be unjust to look at the mother as an individual outside her context.

Chapter 6. RECOMMENDATIONS AND LIMITATIONS

The chapter presents recommendations to the discipline of occupational science and the profession of occupational therapy. Limitations of this study are also outlined. The chapter draws to an end with the conclusion of the study.

6.1. Recommendations

6.1.1 Recommendations to occupational science

“‘Occupational science’ is the study of the human as an occupational being, including the need for capacity to engage in and orchestrate daily occupations in the environment over the lifespan.” (Yerxa *et al.*, 1989:6) This study has explored mothers as occupational beings who engage in the occupation of caring for their child/children with HIV-related NDD. This is an area of research that has not yet been undertaken in the Zimbabwean context. The findings of the study highlight that, despite the burden of the tasks related to caring for their child/children, mothers find significant meaning in being a mother and caring for a child with HIV-related NDD. In spite of being taxed by the demands of caring, mothers remained motivated to care and provide for their child. The findings of this study have also further revealed the transactional perspective of the occupation of being a mother and caregiver, by highlighting the interplay and interdependence between the context and the personal factors that shape the experience of the occupation of caring for a child with HIV-related NDD. Thus, research informed by ethnography, further exploring how the social context of culture influences the meaning-making process of the mothers through occupation, would be of interest. In addition to the process of meaning-making inherent in the mothers’ ideas, there is need to further explore various ways in which mothers orchestrate their daily occupations to accommodate the care of their child, as well as the value they place on the care of their child.

6.1.2. Recommendations to occupational therapy practice

The study highlighted the transactional nature of the occupation of caring for a child with HIV-related NDD by describing how the occupation is shaped by both personal and contextual factors. Thus, occupational therapy is encouraged to enlarge its scope of practice from focusing on the child with impairment, to include the mother as the primary caregiver who is engaged

in the occupation of caring for the child, in relation to both their context and their own personal attributes. Community outreach programmes for children with HIV-related Neurodevelopmental disabilities in Zimbabwe should also be target mothers of these children, focusing on their everyday living within their context. There is a need for assessment procedures and interventions that can be done in cognisance of the interplay of personal factors and context for mother and child.

Culture expected caring for the children with HIV-related NDDs to be a woman's role despite other duties as being breadwinners. Similar to findings of this study Sherry and Martin (2010) noted how some parts of the African culture can be oppressive and these authors challenged occupational therapists to be advocates of the vulnerable. A human rights perspective to challenging injustices through advocacy is recommended.

Mothers who are highly motivated often become absorbed in the occupation of caring for the child and as a result frequently neglect their own personal needs. As occupational therapists, there is need to think how to juggle the tensions that arise from the mothers' need-to-do for the child at the expense of other occupations that are of significance to them. Interventions that show respect for this balance and support the mothers in their doing for (caring for the child) and their own doing (their own occupations and care for themselves) would promote positive caregiving in the mother. Participatory action research would be a useful research tool to guide the development of client centred and relevant interventions for the mothers.

In summary there is a clear need, from an occupational perspective, to formulate a supporting framework for mothers caring for children with HIV-related NDD.

6.1.3 Recommendations for further research

Recommendations for further studies are as follows:

1. The study has highlighted how resilience can be viewed as an element of character within the mothers and how this trait has contributed to the shaping of their caring experiences. However there is a need for further exploration of this resilience in carers using grounded theory methodology, with the intention of developing a theory on resilience from an occupational perspective. Research would focus on the impact of

resilience on the mother's health, caring role and occupations rated meaningful to the mothers. An occupational perspective would provide a lens for examining how resilience shapes everyday doings in the face of difficulties, especially in the African context.

2. Occupational therapy has a role to play in enabling and supporting mothers to care for children with HIV-related NDD. Participatory action research with mothers can be used to co-create an intervention which supports them and their family's occupational needs.
3. Mothers in this study revealed that caring for a child with HIV-related NDD is an all-consuming role and there are lots of things to be done to a set timetable. A quantitative research on time allotment and use by mothers caring for children with HIV-related NDD would reveal the extent to which caring is placing extra stress on their time for other duties. The research should also be aimed at finding out how mothers organize and spend their days in the face of caring for a child with HIV-related NDD.

6.2 Limitations of the study

6.2.1 Sampling

Although the researcher used maximum variation to select participants for the study, the participants were limited only to those serviced by Harare Central Hospital. The catchment area for Harare Central Hospital is the high density suburbs and the rural areas where medium- to low-income people live. The affluent community often accesses rehabilitation services in the private sector and were therefore not included in this study. If recruitment had also been done in other settings, a more variable sample could have been achieved.

Also, recruitment at Harare Central Hospital's CRU gave the researcher access to participants who are already receiving different kinds of support. Their experience may have been different from those mothers who are more home-based and who may not have received any form of support. Although accessing participants at CRU had its challenges, the sensitivity and confidentiality associated with HIV/AIDS made it difficult to penetrate and access participants from different settings, other than through the hospital.

The inclusion criteria limited participants to those that speak Shona and English only. Although these were the most common languages used in Harare (the research setting), inclusion of other participants from different dialects could have made the findings richer.

6.2.2 Data Collection Method

The method used for data collection, which was tape-recorded interviews, relied mostly on the memory of the mothers. Relying on memory has implications of bias to the findings.

The study focused on one aspect of the experience of being a mother – that is the experience of caring for a child with NDD. A more extensive study of exploring more broadly the phenomenon of “being a mother” of a child with HIV-related NDD, could capture more diverse experiences beyond the experience of caring. Such extensive study was outside the focus of this study.

6.3 Conclusion

A descriptive phenomenological approach was used to explore the lived experience of caring for a child with HIV-related NDD, with the caregiver primarily being their biological mothers. The methodology allowed the researcher and the mothers to engage in phenomenological conversations that generated descriptions of the meaning and essence the mothers ascribed to their experiences of caring for their child/children with HIV-related NDD. Mothers expressed how caring for the child was a responsibility that needed to be theirs and one that they could not and (would not easily) share with others. Despite the difficulty and demanding nature of the tasks linked to the caring role, mothers reconsidered the caregiver burden. A key finding of this study was the meaning-making process of the caring role and how it influenced the experiences of the mothers. Mothers expressed their resilience in caring for a child with HIV-related NDD. In fact, caring was a fulfilling role to the mothers. Also, mothers’ experiences shed more light on the transactional nature of the occupation of caring for a child with HIV-related NDD, showing that their caring experiences were shaped by the personal factors as well as the contextual ones.

REFERENCES

1. Aiken, F. F., Fourt, A.M., Cheng, I.K.S., & Polatajko, H.J. (2011). The meaning gap in occupational therapy: Finding meaning in our own occupation. *Canadian Journal of Occupational Therapy*, 78, 294-302.
2. Akujobi, R. (2011). Motherhood in African literature and culture. *Comparative literature and culture*. Retrieved from <<http://docs.lib.purdue.edu/clcweb/vol13/iss1/>> on 28 January 2014.
3. Birdthistle, I. J., Floyd, S., Mwanasa, S., Gwiza, E., & Glynn, J.R. (2011). Child sexual abuse and links to HIV and orphanhood in Zimbabwe. *Journal of Epidemiology and Community Health*, 65(12), 1075-1082.
4. Bourke-Taylor, H., Howie, L. & Law, M. (2010). Impact of caring for a school-aged child with a Disability: Understanding mothers' perspectives. *Australian Occupational Therapy Journal*, 57, 127-136.
5. Bauman, L.J., Silver, E.J., Draimin, C.H., & Hudis, J. (2007). Children of mothers with HIV/AIDS: Unmet needs for mental health services. *Paediatrics*, e1141-e1147.
6. Carpenter, C. & Suto, M.C. (2008). *Qualitative research for occupational therapists: A practical guide*. London: Blackwell Publishing Ltd.
7. Case-Smith, J. (2009). Occupational therapy's role in supporting family unit. *OTJR: Occupation, Participation and Health*, 29(2), 50-51.
8. Chan, S.W., Williamson, V., & McCutcheon, H. (2009). Comparative study of the experiences of a group of Hong Kong Chinese and Australian women with postnatal depression. *Perspectives in Psychiatric Care*, 45(2), 108-118.
9. Corcoran, M. & Donovan, M. (2010). Description of dementia caregiver uplifts and implications for occupational therapy. *American Journal of Occupational Therapy*, 64(4), 590-595.

10. Creswell, J. (2007). *Qualitative research designs. An iterative approach* (2nd ed.). Thousand Oaks: Sage.
11. Cutchin, M. P., Aldrich, R.M., Bailliard, A. L., & Coppola, S. (2008). Action theories for occupational science. The contributions of Dewey and Bourdieu. *Journal of Occupational Science*, 15(3), 57-165.
12. D'Aura, J. P., Christian, B. J., & Miles, M. S. (2006). Being there for my baby: Early response of HIV-infected mothers with an HIV-exposed infant. *Journal of Paediatric Healthcare*, 20, 11-18.
13. Daffy, L. (2005) Suffering, shame and silence: The stigma of HIV/AIDS. *Journal of the Association of Nurses in AIDS care*, 16(1), 13-20.
14. Demmer, C. (2011). Experience of families caring for an HIV-infected child in KwaZulu-Natal, South Africa: An exploratory study. *Aids Care*, 23(7), 873-879.
15. Dickie, V., Cutchin, M. P., & Humphry, R. (2006). Occupation as transactional experience: A critique of individualism in occupational science. *Journal of Occupational science*, 13(1), 83- 93.
16. Doare, K.L., Bland, R., & Newell, M.L. (2012). Neurodevelopment in children born to HIV-infected mothers by infection and treatment status. *Paediatrics*, 130, e1326-e1344.
17. Duncan, E. M. (2009). Human Occupation in the context of chronic poverty and psychiatric disability. Unpublished doctoral thesis. Department of Psychology. University of Stellenbosch.
18. Farah, J., & McColl, M. (2008). Exploring prayer as a spiritual modality. *Canadian Journal of Occupational Therapy*. 75 (1), 5 – 13.
19. Green, S. (2007). “We are tired not sad” benefits and burdens of mothering a child with a disability. *Social Science and Medicine*, 63, 150-163.
20. Graham, F., Rodger, S., & Ziviani, J. (2009). Coaching parents to enable children's participation: An approach to working with parents and their children. *Australian Occupational Therapy Journal*, 56(1), 16-23.

21. Hammell, K. W. (2004). Dimensions of meaning in the occupations of daily life. *Canadian Journal of Occupational Therapy*, 5 (71) 296-305.
22. Hammell, K.W. (2010). Contesting assumptions in occupational therapy. In Curtin, M., Molineux, M., & Supyk-Mellson. *Occupational therapy and physical dysfunction*. Edinburgh: Churchill Livingstone.
23. Hejoaka, F. (2009). Care and secrecy: Being a mother of children living with HIV/AIDS in Burkina Fasso. *Social Science and Medicine*, 869-876.
24. Hocking, C. (2009). The challenge of occupation: Describing the things people do. *Journal of Occupational Science*, 16(3) 140 – 150.
25. I-Fen, L., Holly, R.F., & Hseueh-Sheng, W. (2010). Negative and positive caregiving experiences: A closer look at the intersection of gender and relationships. *Family Relations*, 61, 343-359.
26. Kandawasvika, G., Ogundipe, E., Gumbo, F., Kurewa, E., Mapingure, M., & Stray-Pedersen, B. (2011). Neurodevelopmental impairment among infants born to mothers infected with human immunodeficiency virus and uninfected mothers from three peri-urban clinics in Harare, Zimbabwe. *Developmental Medicine and Child Neurology*, 53(11), 1046-1052.
27. Kielhofner, G. (2008). *Model of human occupation: Theory and application* (4th Ed.). Baltimore Williams & Wilkins.
28. Kimani-Murage, E., Manderson, L., Norris, S.A., & Kahn, A. (2010). You opened our eyes: Caregiving after learning a child's HIV status in rural South Africa. *Health and Social Care in the Community*, 18(3), 264-271.
29. Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy*, 45(3), 214-222.
30. Kuo, A. (2011). A transactional View: occupation as means to create experiences that matter. *Journal of Occupational Science*, 18(2), 131--138.
31. Kuo, C., & Operario, D. (2009). Caring for Aids orphaned children: A systematic review of studies on caregivers. *Vulnerable Children and Youth Studies*, 4(1), 1-12.

32. Kuonza, L.R., Tshuma, C.D., Shambira, G.N., & Tshimanga, M. (2010). Non adherence to the single dose nevirapine regimen for the prevention of mother to child transmission of HIV in Bindura town, Zimbabwe: A cross-sectional analytic study. *BioMed Central Public Health*. retrieved from <http://www.biomedcentral.com/1471-2458/10/218> on 10 December 2013
33. Kubler-Ross, E. (1969). *On death and dying*. Routledge.
34. Lala, A., & Kinsella, E. A. (2011). Phenomenology and the study of human occupation. *Journal of Occupational Science*, 18(3), 195- 209.
35. Larson, E. (2000). The orchestration of occupation: The dance of mothers of mothers. *American Journal of Occupational Therapy*. 54, 269 - 280.
36. Larson, E. (2009). Psychological wellbeing and meaning-making when caregiving for children with disabilities: Growth through difficult times or sinking inward. *American Journal of Occupational Therapy*, 78-86.
37. Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry*. Beverly Hills, CA: Sage.
38. Lin, F. Y., Rong, J., & Lee, T. (2013). Resilience among caregivers of children with chronic conditions: A concept analysis. *Journal of Multidisciplinary Health Care*. (6) 323-333.
39. Ludwig, F. M., Huttgar, B., Russell, R. L., & Watson, K. (2007). How caregiving for children affects grandmothers' meaningful occupations. *Journal of Occupational Science*, 14(1), 40--51.
40. Mbirimtengerenji, J. (2007). Is HIV/AIDS epidemic outcome of poverty in sub-Saharan Africa? *Croatian Medical Journal*, 48(5), 605-617.
41. Ministry of Health and Child Welfare, (2009). Zimbabwe National Health Strategic Plan 2009-2013.
42. Moghimi, C. (2007). Issues in caregiving: The role of occupational therapy in caregiver training. *Topics in Geriatric Rehabilitation*, 269-279.
43. Moustakas, C. (1994). *Phenomenological Research Methods*. Thousand Oaks: Sage.

44. Nelson. (2002). Mothering other than normal children. *Qualitative Health Research*, 12(4), 515-530.
45. Nicholl, H., & Begley, C. M. (2012). Explicating caregiving by mothers of children with complex needs in Ireland: A phenomenological study. *Journal of Paediatric Nursing*, 27, 642-651.
46. Njororai, F., & Njororai, W. W. S. (2013). Older adult caregiver to people with HIV/AIDS in Sub-Saharan Africa: A review if literature and policy implications for change. *International Journal of Health Promotion and Education*, 51(5) 248 – 266.
47. Orne-Glieman, A., Mukotekwa, T., Perez, F., Miller, A., Sakarovitch, C., Chenshaw, M., Engelsmann, B., & Dabis, F. (2006). Strengthening PMTCT through communication. *Tropical Medicine and Internal Health*, 11(3), 341-343.
48. O’Sullivan, A. (2007). AOTA's statement on family caregiving. *American Journal of Occupational Therapy*, 61(6), 710.
49. Phelan, S., & Kinsella, E.A. (2013). Occupation and identity: Perspectives of children with disabilities and their parents. *Journal of Occupational Science*, 1-25.
50. Patton, M. (2002). *Qualitative research and evaluation methods*. Thousand Oaks: Sage Publications.
51. Pickens, N. D., & Pizur-Barnekow, K. (2009). Co-occupation: Extending the dialogue. *Journal of Occupational Science*, 16, 151-156.
52. Pierce, D. (2003). How can occupation base of occupational therapy be strengthened? *Australian Occupational Therapy Journal*, 50, 1-2.
53. Potterton, J. Stewart, A., Cooper, P., Goldberg, L., Gajdosik, C., & Baillieu, N. (2009a). Neurodevelopmental delay in children infected with human immunodeficiency virus in Soweto, South Africa. *Vulnerable Children and Youth Studies*, 4(1), 48-51.
54. Potterton, J., Stewart, A., & Cooper, D. (2009b). Parenting stress of caregivers of young children who are HIV-positive. *African Journal of Psychiatry*, 10, 210-214.

55. Price, M.P., & Miner, S. (2009). Mothering becoming: Learning to read Mikala's signs. *Scandinavian Journal of Occupational Therapy*, 16, 68-77.
56. Ramugondo, E. (2004). Play and playfulness: Children living with HIV/AIDS. In Swarts, L. and Watson, R. Transformation through occupation: Human occupation in context (pp. 171-185). London: Whurr.
57. Ramugondo, E., & Kronenberg, F. (2013). Explaining collective occupations from a human relations perspective: Bridging the individual-collective dichotomy. *Journal of Occupational Science*, 1-14.
58. Savin-Baden, M., & Major, C. H. (2012). Qualitative Research: The essential guide to theory and practice. New York: Routledge.
59. Sherry, K. (2010). Culture and cultural competence for occupational therapists in Africa. In Alers, V. C., and Crouch, R., *Occupational therapy: An African perspective*.
60. Sherry, K., & Martin, Z. I. (2010). HIV, Occupational performance and the role of occupational therapy. In Alers, V. C., and Crouch, R. *Occupational therapy: An African perspective*.
61. Silverman, D. (2006). *Interpreting qualitative data* (3rd ed.). Thousand Oaks: Sage.
62. Stein, A., Krebs, G., Richter, L., Tankins, L., Rochat, T., & Bennish, M. (2005). Babies of a pandemic. *Archives of Disease in Childhood*, 90(2), 116-118.
63. Sungh, D., Chaudor, S.R., Escobar, M., and Kalichman, S. (2011). Stigma, burden, social support, and willingness to care among caregivers of PLWHA in home based care in South Africa. *AIDS Care*, 23(7), 839-845.
64. Townsend, E. & Wilcock, A.A. (2004). Occupational Justice and client centered practice: A dialogue in process. *Canadian Journal of Occupational Therapy*, 71(2), 75-87.
65. Townsend, E., Stone, S.D., Angelucci, T., Howey, M., Johnson, D., & Lawlor, S. (2009). Linking occupation and place in community health. *Journal of Occupational Science*, 16(1), 50-55.

66. UNAIDS. (2012). Global report on HIV/Aids. Accessed on 23 January 2013 on www.unaids.org/en/media/unaids/contentassets/documents/epidermiology/2012/gr2012/2012/120-unaids-global-report-2012-with-annexes-en.pdf.
67. UNAIDS, (2008). Caregiving in the context of HIV/AIDS. Accessed on 23 January 2013 on www.un.org/womenwatch/daw/egm/equalsharing/EGM-ESOR-2008-BP-4%20UNAIDS-Expert.%20Panel-paper-%final.pdf.
68. Vallido, T., Wilkes, L., Carter, B., & Jackson, D. (2010). Mothering disrupted by illness: Narrative synthesis of qualitative research. *Journal of Advanced Nursing*, 66(7), 1435-1445.
69. Van Graan, A., Van de Walt, E., & Watson, M. (2007). Community-based care of children with HIV in Potchefstroom, South Africa. *African Journal of Aids Research*, 6(3), 305-313.
70. Van Rie, A., Mupuala, A., & Dow, A. (2008). Impact of the HIV/AIDS epidemic in the neurodevelopment of preschool aged children in Kinshasa, DRC. *Paediatrics*, 122-128.
71. Van Mannen, M. (1997). *Researching lived experience: Human science for an action sensitive pedagogy*. London, ON: Althouse Press.
72. Watson, R., & Lagerdien, K. (2004). Occupational therapy defined for district rehabilitation. *South African Journal of Occupational Therapy*, 34(1), 11-13.
73. Wilcock, A. (1999). Reflections on doing, being and becoming. *Australian Occupational Therapy Journal*, 46, 1-11.
74. Wilcock, A. A. (2006). *An occupational perspective of health*. Thorofare, NJ: Slack.
75. World Health Organisation [WHO]. (2008). Epidemiological fact sheet on HIV/Aids: Core data on epidemiology and response, Zimbabwe. Accessed on 8 March 2012 at www.who.int/globalatlas/predefinedReports/EFS2008/full/EfS2008_ZW.pdf
76. World Health Organisation (2011). Word report on Disability. Accessed on 24 June 2013 at www.who.int/disabilities/world-report/2011/report.pdf.

77. Yerxa, E., Clark, F., Frank, G., Jackson, C., Pierce, D., & Zemke, R. (1989). An introduction to occupational science: A foundation for occupational therapy in the 21st century. *Occupational Therapy in Health Care*, 6, 1-17

APPENDICES

APPENDIX A: LITERATURE REVIEW MAPPING

Data Base	Search Terms Used
<ul style="list-style-type: none"> • Academic Search Premier • Africa Wide Information • CINAHL • ERIC • Google Scholar • Health Science: Nursing/Academic Edition • Medline • Psych Articles • PsycINFO • PubMed • University of Cape Town Library 	<ul style="list-style-type: none"> • Caregiving • Child Caring in HIV/AIDS • Caregiving Challenges • Caregiving Meaning • Caregiving Occupation • HIV/AIDS • Occupation • Qualitative Research • Phenomenology

APPENDIX B: INFORMATION LETTER (ENGLISH)



UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences

School of Health and Rehabilitation Sciences



Divisions of Communication Sciences and Disorders,
Nursing and Midwifery, Occupational Therapy,
Physiotherapy
F45 Old Main Building, Groote Schuur Hospital,
Observatory 7925
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Dear Participant

Re: Mother's' experience of caring for a child with HIV-related Neurodevelopmental disorders.

My name is Nyaradzai Dangarembizi and I am a postgraduate student (MSc) in the department of Occupational therapy at the University of Cape Town, South Africa. In partial fulfilment of my master's degree, I am conducting a study in Zimbabwe on the mother's experience of caring for a child with HIV-related neurodevelopmental disorders. The study has been approved by University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee (HREC ref no 182/2013) and the Medical Research Council of Zimbabwe (MRCZ ref no. B/501) and permission has been granted by the Harare Hospital Children's rehabilitation department. I am inviting you to take part in this study.

Purpose of Study

The purpose of this study is to get an understanding of the experience of caring for a child with HIV-related neurodevelopmental disorders from mothers who are caring for such children. Neurodevelopmental disorders are disabilities associated primarily with the nervous system and children with this condition do not develop normally as other children would. They may have difficulties with language and speech, walking, crawling, behaviour, memory, learning or other disabilities. The study will provide information to the body of knowledge of health practitioners and strategies for improving the quality of life of mothers of children with HIV related neurodevelopmental disorders will be formulated.

Participant Selection

You are being invited to take part in this research because we feel that your experience as a mother who is caring for a child with HIV-related neurodevelopmental disorder, can contribute much to our understanding and knowledge of caregiving.

Procedures involved in the study

Participation in this study is on voluntary basis, thus, upon accepting to participate in the study, you will be asked to sign an informed consent form. A date and time convenient to you will be set for the first interview at the Children's rehabilitation unit premises or any other place that is quiet, convenient and you feel comfortable to be interviewed at. The interviewer will not come to your home without your approval. Two interview sessions will be held at a quiet place of your choice. Each interview is likely to take 90 minutes. Another appointment for the second interview will be made at the end of the first interview. If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question. No one else (including your child) but the interviewer will be present unless you would like someone else to be there. The information recorded is confidential, and no one else except the researcher will have access to the information documented during your interview. The entire interview will be tape-recorded, but no-one will be identified by name on the tape. And information recorded will be confidentially handled. In a bid to make sure that your information is correctly interpreted, the researcher will come to you again with the processed information asking for your verification and input.

Risks and Discomforts

In this study, the researcher will ask you to share with us some very personal experiences of caregiving, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question or take part in the interview if you don't wish to do so, and that is also fine. You do not have to give us any reason for not responding to any question during the interview.

In the event that you or the researcher feels that you need counseling and psychosocial support services, a referral will be made to CRU clinic.

Benefits and/ Compensation

Participation in this study is on voluntary basis. There is no remuneration for taking part in this study. Your participation is however likely to help me get an understanding of the lived experience of caring for a child with HIV-related neurodevelopmental disorders. . Refreshments will be served during the interviews.

Voluntary Participation

If you feel you do not want to participate in this study for any reason you are free to do so. The normal treatment and services that you would need will not be affected in any way. You may stop participating in the research at any time that you wish and you will not be forced to give an explanation.

Confidentiality

The research being done at the community clinic may draw attention and if you participate you may be asked questions by other people in the community. We will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about yourself that you provide will have a number on it instead of your name. Only the researchers will know what your number is and will keep this information in a secure location.

Contact Details

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact any of the following:

The Researcher: Nyaradzai Dangarembizi
Cell phone Number: +263 775 428 950
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College of Health Sciences
Department of Rehabilitation
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Or

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APPENDIX B 1: INFORMATION LETTER (SHONA)



UNIVERSITY OF CAPE TOWN
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School of Health and Rehabilitation Sciences



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Vadiwa Vabereki

Re: Tsvakiridzo pamusoro pamararamiro ana amai vanochengeta vana vanematambudziko pakukura kwavo zvichikonzerwa nechirwere cheutachiwona hwe HIV.

Zita rangu ndinonzi Nyaradzai Dangarembizi, ndiri mudzidzi wemagwaro epamusorosoro muchikamu chinoongorora zvimitezo che Occupational therapy.

kuchikoro cheUniversity yekuCape Town kuSouth Africa. Kuzadzikisa chidzidzo chemagwaro angu, ndirikuita tsvakiridzo muZimbabwe kuna ana amai vaneruzivo nemachengeterwo evana vanematambudziko pakukura kwavo zvichikonzerwa nechirwere cheutachiwona hwe HIV. Tsvakiridzo iyi yakabvumirwa neUniversity of Cape Town Faculty of Health Sciences Human Research Ethics Committee (HREC ref no. 182/2013) uyezve ne Medical Research Council of Zimbabwe (MRC ref no. B/501). Pamusoro pezvo vakuru veHarare Central Hospital vakabvumidza kuti tsvakiridzo iyi iitirwe pamusha wavo we Children's rehabilitation Unit. Ndinokukokayi kuti mupinde mutsvakiridzo yangu iyi.

Chinangwa chetsvakiridzo iyi

Chinangwa chetsvakiridzo iyi, kuti tive nekunzwisisa basa rekuchengeta vana rinoitwa nana amai vari kurarama varimazviri nguva dzose. Tsvakiridzo iyi inotarisirwa kutipa ruzivo runeudzamu kuchidzidzo cheOccupational Therapy uye zvichabatsira kugadzira hwaro rwedzidzo tichitarisa nzira dzekubatsira nadzo pakuchengetwa kwevana nana amai vane dambudziko rekusakura zvakanaka zvichikonzerwa neutachiwana hwe HIV.

Sarudzo Yevachave mutsvakiridzo

Munokokwa kuti muve munopawo ruzivo rwenyu mutsvakiridzo iyi nekuti takaona kuti ruzivo rwenyu saamai vanochengeta mwana ane dambudziko pakukura kwake zvichikonzerwa nechirwere cheshuramatongo, ndimi mungabatsira zvakanaka kuti tive nekunzwisisa pamusoro pemachengeterwo evana ava.

Nzira Ichashandiswa Pakuita Tsvakiridzo

Mushure mekunge matendera kupinda mutsvakiridzo iyi, muchabvunzwa mibvunzo muzvikamu zviviri zvakasiyana. Muchikamu chekutanga muchasarudza zuva pamwe nenguva yamunoona yakafanira kuti muvhunzwe mibvunzo yacho, zvichiitirwa panzvimbo yeChildren's Rehabilitation Unit (CRU). Mibvunzo inotarisirwa kutora maawa maviri, mushure mezvo kozoitwa hurongwa hwekuzoita chimwe chikamu chemibvunzo. Kana maona zvakakuomera kupindura mimwe yemibvunzo yamuchabvunzwa munotenderwa kubuda pachena kuti hamukwanisi kupindura kuitira kuti mubvunzi aenderere mberi. Hapana mumwe munhu anenge aripo munguva yekunge muchibvunzwa iyi kunze kwekunge mada imimi kuti kuve nemumwe munhu. Mhinduro dzamuchapa pamibvunzo yamuchabvunzwa ichachengetwa zvakavandika uye hapana mumwe munhu (kunyangwe mwana wenyu) anotenderwa kuve nemukana wekuona mhinduro dzenyu kunze kwemutsvakiridzi chete. Zvamuchataura muzvikamu zvemibvunzo zvichange zvichitapwa nechivhitivhiti (tape recorder) asi pasina kudomana kwemazita pakutapwa apa uye zvichange zvachengetwa zvakavandika.

Njodzi kana Zvakamanika

Mutsvakiridzo iyi muchave nekubvunzwa uye nekupawo ruzivo rwako munezvimwe zvakavandika, pamwe unogona kuomerwa, kukurukura kana kupindura zvimwe zviri muhurukuro yacho, wakasununguka kupindura kana kusapindura kana wamanikwa Haufanire kutipa chikonzero chekutadza kwako kupindura mibvunzo yacho.

Mubhadharo kana Zviripo

Hapana mubhadharo uripo kwauri, asi kuti kupa ruzivo rwako kuchatibatsira kuti tive nekunzwisisa kuzere nemachengeterwo evana vane dambudziko iri. Mari yekufambisa pamwe nechikafu muchange muchipihwa pazvikamu vemibvunzo asi hakuna mubhadharo waunopihwa mushure wave mumwe wetsvakiridzo.

Kuve Mutsvakiridzo

Hapana kumanikidzwa kuripo kuti uve mutsvakiridzo iyi uye hazvikutadzise kuwana rubatsiro rwako renguva dzose pachipatatra apa. Unotenderwa kusava mumwe wetsvakiridzo chero panguva yawada uye haumanikidzwi kupa chikonzero.

Zvakavandika

Tsvakiridzo ichaitwa muchipatara chemunharaunda zvichava zvichakwezva pfungwa dzevazhinji zvekuti anenge apinda mutsvakiridzo achabvunzwa nevanhu vekunze, asi tinovimbisa kuti hapana kushambadziwa kwezvaunenge wataura asiri muchikwata chevarikuita tsvakiridzo. Zvese zvauchataura zvichange zvichizivikanwa nemucherechedzo yechiverengo kwete zita rako. Varidzi vetsvakiridzo ndivo vega vanenge vachiziva chiverengo chako uye zvichawanikwa mutsvakiridzo zvichave zvachengetwa zvakavandika.

Kwekundiwana

Kana paine ane mibvunzo, unogona kubvunza iye zvino kana pakufamba kwetsvakiridzo. Kana uchishuwira kuzondibvunza munguva inotevera munogona kuzondibata pa:

The Researcher: Nyaradzai Dangarembizi

Cell phone Number: +263 775 428 950

Address: University of Zimbabwe,

College of Health Sciences

Department of Rehabilitation

Private Bag A198

Avondale, Harare

Kana vakuru vangu

The Supervisors: Pam Gretscher & Amshuda Sondag

Cell Phone Number: +27 79 883 6813/

+27 82 486 9596

Address: University of Cape Town,

Faculty of Health Sciences

Department of Occupational Therapy

Old Main Building, F56 Rm 73,

Groote Schuur Hospital

7925 Observatory, Cape Town

Kana Kuti

The Human Ethics Research Chairman:

Professor Blockman

Telephone +27 21 406 6338

Address University of Cape Town,

Faculty of Health Sciences, HREC

Human E52-24,

Groote Schuur Hospital 7925

Observatory, Cape Town

APPENDIX C: INFORMED CONSENT (ENGLISH)

Title of Project: *An understanding of the lived experience of caring for a child with HIV-related neurodevelopmental disorder.*

Principal Researcher: Nyaradzai Esther Dangarembizi

Project Supervisors: Pam Gretschel and Amshuda Sondag

Institution: University of Cape Town, Department of Health and Rehabilitation Sciences

I, _____ have read (or the sheet has been read to me) the information sheet. I understand what is required of me and I have had all my questions answered. I do not feel that I am forced to take part in this study and I am doing so of my own free will. I know that I can withdraw at any time if I so wish and that it will have no bad consequences for me.

I understand that audio recordings of interviews will be taken during the study

I agree to being audio recorded

Yes

☐

No

☐

Signed:

Participant

Date and place

Researcher

Date and place

Witness

Date and Place

APPENDIX C 1: INFORMED CONSENT (SHONA)

Musoro Wetsvakuridzo: *Kunzwisisa pamusoro peruzivo rwavana amai vanochengeta vana vanedambudziko ekusakura zvakanaka vichikonzerwa nechirwere cheutachiwona.*

Mutsvakiridzi: Nyaradzai Esther Dangarembizi

Vakuru wemuTsvakiridzi: Pam Gretscher and Amshuda Sunday

Chikoro: University of Cape Town, Departmental of Health Rehabilitation Sciences

Ini _____ ndaverenga (ndaverengerwa na _____) bepa reziviso. Ndanzwisisa zvinodikanwa kubva kwandiri uye ndawana ndichipindurwa mibvunzo yangu yese. Handisi kunzwa sekunge ndamanikidzwa kupa ruzivo rwangu mutsvakiridzo iyi uye ndirikuita nekuda kwangu. Ndinoziva kuti ndinogona kungosiya kuve mutsvakiridzo pandinenge ndadira uye hapana zvazvinokonzeresa pakurarama kwangu.

Ndanzwisisa kuti hurukuro dzetsvakiridzo iyi, dzichange dzichirekodhiwa.

Ndinobvuma kurekodhiwa

Yes

☐

No

☐

Signed

Abvunzwa

Zuva nenguva

Mutsvakiridzi

Zuva nenguva

Mutsigiri

Zuva nenguva

APPENDIX D: INTERVIEW PROTOCOL (ENGLISH)

Project title: *Mother's lived experience of caring for a child with HIV-related neurodevelopmental disorder.*

Time of interview:

Date:

Place:

Interviewer:

Position of interviewer:

The study undertakes a phenomenological approach to understand the mothers lived experience of caring for a child with HIV-related neurodevelopmental disorder, their challenges and meanings they draw from this caregiving occupation. In-depth interviews will be used to collect data and results of the study will inform occupational therapy practice.

Interviewee:

Demographic Information of the participant:

Marital Status:

Level of Education:

Occupation:

How many children do you have?

Number of children with neurodevelopmental disorder:

Questions:

Tell me about your child?

Can you describe to me how it feels to be his mother?

Are there any positive elements to being a mother to this child?

What are the challenges that you experience in caring for this child?

Do you receive any kind of support in relation to caring for this child?

If so what kind of support is this?

What could be done to support your caregiving role?

(Thank you for participating in this interview. All information discussed is confidential and will be handled with utmost care. We will get back to you if we need more information or your assistance. Once again thank you)

APPENDIX D 1: INTERVIEW PROTOCOL (SHONA)

Tsvakiridzo: *Amai vaneruzivo rwekuchengeta mwana ane dambudziko rekusakura zvakanaka zvichikonzerwa nekurwara neutachiwona.*

Nguva yabvunzwa mibvunzo:

Zuva:

Nzvimbo:

Anga achibvunza mibvunzo:

Anga achibvunzwa mibvunzo:

Mamiriro emunhu anga achibvunzwa: Tsvakiridzo iyi ichatipa kunzwisisa kune udzamu tichitarisa anamai vanochengeta vana vane dambudziko iri, matambudziko avanosangana navo uye nematorero avanoita basa ravo rekuva muchengeti wemwana anedambudziko iri. Muzvizare mibvunzo ichaitwa ichashandiswa kutora ruzivo nezvichabuda mutsvakiridzo dzekurapa kwedu.

Mubvunzwi

Marital Status:

Makadzidza kusvika Papi:

Basa ramunoita nderipi:

Mune vana vangani?

Ko mune vana vangani vene chirwere che neurodevelopmental disorder:

Mibvunzo

1. Nditaurirei nezve mwana wenyu?

2. Nditsanangurirei kuti munonzwa sei kuve mai vake?
3. Ndezvipi zvinobatanidza rufaro rwekuva amai vake?
4. Ndezvipi zvinhinga mupini zvamunosangana nazvo pakuchengeta mwana uyu?
5. Zvii zvingaitwa pakubatsira chinzvimbo chenyu chekuve muchengeti?

(Tinotenda nekupa ruzivo rwenyu, Zvese zvawanikwa muhurukuro iyi zvichave zvakachengetedzwa zvakavandika.Tichadzoka kwamuri kana toda rumwe ruzivo.Tatenda zvakare)

APPENDIX E: SECOND LINE INTERVIEW GUIDE

Demographics

It's my responsibility

How exactly or to what extent is caregiving your responsibility?

Caregiving as an Occupation

What do you see caregiving to be and what does it involve?

Is there any difference in caring for this child as compared to caring for other children?

Which occupations are meaningful and why?

Positive experience of being a mother of a child with HIV-related NDD

What is the great/fulfilling thing about being this child's mother?

Does play happen and if so how does it happen?

Negative Experience of being a mother of a child with HIV-related NDD

What are the negatives about caregiving for this child? How do you cope?

APPENDIX E 1: SECOND LINE INTERVIEW GUIDE (SHONA)

Ruzivo pamusoro pemubvunzwi

- Munowona kuchengeta mwana anehurema hwakakonzerwa neHIV riri basa ramunotarisirwa kuita here?
1. Seyi muchiwona sekuti kuchengetwa kwemwana wenyu anehurema hwakakonzerwa neHIV sebasa ramunotarisirwa kuita?
 2. Munowona kuchengeta mwana uyu riri basa rakaita seyi?
 3. Ndezvipi zvinhu zvamunoita pakuchengeta mwana uyu?
 4. Pane musiyano here pakuchengeta mwana ane hurema hwakakonzerwa neHIV nekuchengetawo vamwe vana vasina chirwere?
 5. Ndeapi mabasa amunowona akakukosherayi muhupenyu?
Nemhaka yei muchiwona mabasa iwaya akakukosherayi?
 6. Ndezvipi zvinokufadzayi maererano nekuchengeta mwana uyu?
 7. Muno mbowana mukana wekutamba nemwana wenyu here? Kana mhinduro iri hungu, nditsanangurireyi zviro zvezvimwe zvamunoita kana muchitamba nemwana?
 8. Ndezvipi zvinokusuwisayi kana kukuwomerayi maererano nekuchengeta mwana wenyu?
 9. Munozvigona seyi zvekuchengeta mwana ane hurema hwakakonzerwa neHIV?

APPENDIX F: APPROVAL FROM HARARE CENTRAL HOSPITAL

Telephone: 621100-19
Fax: 621157



Reference:

HARARE CENTRAL HOSPITAL
P. O. Box 51 14

SOUTHERTON

Harare

24 April 2013

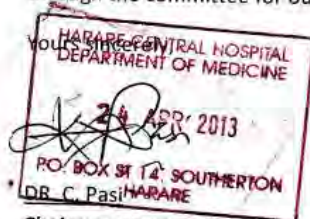
Miss N.E. Dangarembizi
Department of Rehabilitation
P.O. Box A178
Avondale
HARARE

Dear Nyaradzai,

REF: MOTHER'S' LIVED EXPERIENCES OF CARING FOR A CHILD WITH HIV-RELATED NEURODEVELOPMENTAL DISORDER/S.

I am glad to advise you that your application to conduct a study entitled: **Mother's' Lived Experiences of Caring for a Child with HIV-Related Neurodevelopmental Disorder/s**, has been approved by the Harare Hospital Ethics committee.

You are advised to avail the results of your study whether positive or negative to the hospital through the committee for our information.



Chairman Harare Central Hospital Ethics Committee

APPENDIX G: HREC ETHICAL APPROVAL

UNIVERSITY OF CAPE TOWN



Faculty of Health Sciences
Faculty of Health Sciences Human Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: sumayah.ariefdien@uct.ac.za
www.health.uct.ac.za/research/humanethics/forms

18 March 2013

HREC REF: 182/2013

Miss NE Dangarembizi
c/o Ms P Gretsche
Occupational Health
F-floor
OMB

Dear Miss Dangarembizi

PROJECT TITLE: MOTHER'S LIVED EXPERIENCES ON CARING FOR A CHILD WITH HIV-RELATED NEURODEVELOPMENTAL DISORDER/S

Thank you submitting your study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the HREC has **formally approved** the above mentioned study.

Approval is granted for one year till the 28 March 2014.

Please submit a progress form, using the standardised Annual Report Form, if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC. REF in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

aAriefdien

APPENDIX H: APPROVAL FROM MEDICAL RESEARCH COUNCIL OF ZIMBABWE

Telephone: 791792/791193
Telefax: (263) - 4 - 790715
E-mail: mrcz@mrcz.org.zw
Website: <http://www.mrcz.org.zw>



Medical Research Council of Zimbabwe
Josiah Tongogara / Mazoe Street
P. O. Box CY 573
Causeway
Harare

APPROVAL

Ref: MRCZ/B/501

06 June, 2013

Nyaradzai Esther Dangarembizi
University of Cape Town
Department of Occupational Therapy
Old Main Building F56 Room 73
Groote Schuur Hospital 7925
Cape Town

RE:- Mother's Lived experience of caring for a child with HIV- Related Neurodevelopmental disorder/s

Thank you for the above titled proposal that you submitted to the Medical Research Council of Zimbabwe (MRCZ) for review. Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to conduct the above titled study. This is based on the following documents that were submitted to the MRCZ for review:

- Research Protocol
- Research Protocol Summary
- Informed Consent Form (English and Shona)
- Interview Guide (English and Shona)

- **APPROVAL NUMBER** : MRCZ/B/501
This number should be used on all correspondence, consent forms and documents as appropriate.
- **TYPE OF REVIEW** : Expedited
- **EFFECTIVE APPROVAL DATE** : 06 June 2013
- **EXPIRATION DATE** : 05 June 2014

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Website should be submitted three months before the expiration date for continuing review.

- **SERIOUS ADVERSE EVENT REPORTING:** All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Website.
- **MODIFICATIONS:** Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Website is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY:** On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Website.
- **QUESTIONS:** Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on mrcz@mrcz.org.zw
- **Other**
- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully

**MRCZ SECRETARIAT
FOR CHAIRPERSON
MEDICAL RESEARCH COUNCIL OF ZIMBABWE**



PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH

APPENDIX I: SIGNIFICANT STATEMENTS FROM PARTICIPANTS

Participant: Nomsa

When I got pregnant I gave birth before his actual time he was premature, he stayed in an incubator for about 2 weeks, so ever since that time, I got ill and was hospitalised at Parirenyatwa. My child was home with his grandmother and I was not breastfeeding him.

So we started noticing that he had a problem on his neck and one of his side was not working he uses one side, so I don't know maybe it was caused by the position he was in the incubator, I am not sure there, if it's the actual cause of the problem and also he cannot seat or stand and even crawl.

He needs support when he is seated; he needs a seat, when he will be relaxing, if you place him down alone he falls.

When we are playing with him, we talk stories and all sorts of things, but he does not talk.

It shall be well with time because at first he could not do anything but now he is able to do this to his hands (bringing them together). So now he can hold things.

Yes, then I did, I was so worried but through counselling sessions explaining to us and seeing other children and doctors telling us.

What makes me excited is just having him as there are some out there who do not have children; I used to cry that why was I given one child, Should I stay with only one; If only God was to see me and bless me with another child and it happened? He gave me another child so I am just excited with that.

I am happy with that, I have to, and who could it had been done to.

Because I am the mother.

There is nobody else who can take care of him.

At the moment, my child is someone on medication, I don't feel safe to give him to someone to take care of him, like 'gogo' (grandmothers) or the aunties, because I know better his timetable for pills, but there are other who come wanting to go with the child, but because of his situation, I just tell them that he is still young.

I refuse because I always want to manage his timetable for pills.

Yes, some people will make mistakes or forget the timetables for pills and they will deliberately not give him the pills but as for me, as his mother, I make sure that just after giving him his food, I give him pills.

I don't forget because we share the same timetable, when I take my pills that is when I also give him his.

What makes me to feel that I am the best person to take care of the child is the pain that I got during labour, it gives strength that I should be able to take care of my own child.

The elder one did not have any problems so he could go wherever he wants even for holidays, relatives would come take him to their places for holiday. But with him I just fill I should take the responsibility alone.

It's not easy but I am the mother.

At the moment its difficult in the sense that he can't sit alone so he is in a situation that he is always on my back or in my hands like this, you can't live him alone where I am is where he is.

Because it is just so difficult to take care of such a child in such a condition and being able is so important to me.

Socialising with other women.

There are others who wish to have children because they don't have, but I greatly appreciate that at least I have him although he is a problem.

There is nothing that pains me but I am encouraged and given hope at the workshops that we attend, they comfort. At times it affects me as I think a lot that why my child is in this condition but I try to accept it.

I just tell myself that this is what is there and I should accept it.

I wanted to ask, I have heard that children on ART therapy do not survive up to 7 years of age – is it true?

Participant: Tinashe

As a parent, as a mother and the condition of my child, I just feel I have to take care of him myself more than anyone else. You can have a sister, you can have a maid but they don't have that love as that of mother.

Yes, it can be my role, but even if I get someone to stay with, I should also take part of it. Most of the duties that need to be done for my child I need to do it myself. Even my husband said if I am to get a maid that maid should be for the other kids and I be the maid of my own child because I understand better the child's needs. If you get a maid you need to train her for some time so that she knows what is needed on him, his food, and his exercises so I know better. It is so hectic to start teaching somebody, so I just do it alone.

We share the responsibility with my husband.

Yes, in our culture it is mother's responsibility to take care of the children while the fathers go out there to look for money for upkeep.

I don't know because if you look at ti my child is totally different from a child with cerebral palsy, and he is always smart, so I don't know maybe because he can't walk, I am not sure. But as for me, I am not affected with that.

It is tiresome to take care of such a child with this condition, there is a lot to do for them, so it is just difficult to give somebody else the best is to do it yourself.

It is not me but it was planned that way, that on your third child it be like this. There is no one who applies for a disabled child or for a normal child, it just happens, so you cannot blame yourself why it has happened but to just accept it.

Because my child cannot do most of the things alone like the four year old you can send her to go and fetch some water and she goes. I can send the four years old but not him. She can go to the toilet but he cannot.

I am excited with everything because I see so many changes on him and also understanding each other as a family, everyone understand him.

As for me when it happened I just told myself that this is the way it's just supposed to be (zvazviri ndozvazviri). I did not take sides saying so and so or this one is responsible. I just took it the way it was.

Everything I do for him.

At times yes, like when I am alone, I have a lot of things to do. It needs someone to be around assisting. Doing all the duties alone aa ah (shaking her head) it's difficult. Because the other one needs to go to school, the other one to crèche, it's quite difficult.

There is nothing I can change.... Tinashe's pregnancy came without being planned. I thought I was gaining weight until my husband advised that I go to the clinic. I went there and they did a pregnancy test and they said I was pregnant but had to go for scan to see how old the pregnancy was. The report from the scan showed that I was 3 months pregnant. I got away from that place and told myself that whatever. Whatever God, (chero zvazvaita Mwari).

Just thinking that when my nipples cracked and the blood went into him I felt so bad. I gave my child what he did not deserve; if only it was on me alone.

When he grows up, how he is going to accept it, how is he going to tell others....his ...siblings?

God will be the way; he will give us the answers.

All he does just excites me, he changes every day. Each and every day he does something that is very amusing, besides being naughty. If he doesn't become naughty you definitely want to find out.

If I place him with others at CRU I ask myself, why am I here, because he is even much better than others?

I have told myself that women are supposed to carry the burden. It was given to me for a reason so I can't say go and stay with aunt. She will come and see him here and not go with him no. that way I feel secure.

At times I forget that I have a bigger child. I am just giving attention to him.

As for accepting the child it did not took him time. We stand together.

Participant: Memory

He just woke up one day with a hot temperature. I did not understand what it was. I took him to hospital where we normally get our medication in Epworth. The doctors did their stuff assuming that it was meningitis and what they were saying I do not know much about it. I don't know much about that. So I stayed with him in hospital then was later discharged after 3 weeks. He could not seat, he could not walk or do anything and he had fits, he is now epileptic. We came back and I was referred to visit Parirenyatwa, then was later referred here (CRU) for exercises.

He has gained so much weight at the moment. He is 20 kgs; his weight is too much so travelling with him is a problem. I am even sick also, my chest is nowadays painful.

It's not manageable but because there is nothing you can do about it. That is what (ndozvazviri) is there. You would just say 'whatever'.

I am happy to be his mother, I used to be worried and during the first days, like the time he was ill. I would ask myself why is it happening to me and they said he has Cerebral Palsy, I did not understand it. But hearing from others saying a child with Cerebral palsy is not able to do anything in life. I was so touched and worried. I was just a worrying mother and had nothing to do about it.

Yes. I even lost weight, I got a problem of headaches ever since then, and so they say I am thinking too much. But since coming here we are taught about stress management so I comfort myself (ndozvinyaradza).

I am just happy to be her mother with the improvements I am noticing. Yes I feel so happy because you know if you are in closed doors and you hear Doctors saying this and that and on top of that he got tested and found to be HIV-positive. He won't do anything in life. Some would say now he is a cabbage, he won't be able to do anything, so now with the improvements I feel so happy.

As for me....umm relatives from my side have accepted it but relatives from my husband's side I have faced challenges to the extent we reached a time we never talked especially with my Father in law, as they had heard of our HIV status.

It is hard because as the mother, I am the one who makes sure that the kids have taken their pills, we are given a calendar so I make sure that they took their pills. These days I make sure I have given the all because, like this other day, I left him with my aunty as I went to the hospital. I gave her instructions that he takes two and half in the morning and two and half in the evening, but when I came back there were some pills he had not taken and I asked how come, but she did not even understand, so whenever I travel I go with them together with their medication.

Like now he can safely play with others. He likes soccer a lot, he also like cars so I act as if I am the hooter of his car and this makes him happy. When he hears me making the 'tu tu tu' sound of the hooter, he laughs a lot, he likes it.

It is difficult; I did my own analysis which I am afraid of. With what I saw in my analysis, you just say I don't know what will happen – God. Like when he gets fits he may die so I survived with a fear of what could happen to my child in the future.

What really makes me feel that I should do it is that men lack care like the care that we have as women. You as the mother, you are the one to assess and take the child to the hospital. You are the same person expected to give the detailed information about the child, his medication, health and his progress. Even knowing the due date, it's me who knows, so I see myself as the person who has all the care towards the child.

As for me I can say, I don't have much to say about the society, but to say that people should not look forward to the wife alone, to do everything alone but help each other.

This one (child with NDD) needs me more because of the fits (seizures) that he often does, yes he has fits so you won't be sure what will happen to him if I leave him for long. It is difficult to predict when the fits would occur.

I have love for both of them but I am overprotective of the younger one. This is because the other one knows to do some of things better than him.

The most important to me is giving them their medication, thus the most important to me and making sure that I keep up with the timetable for medication in the morning and the evening. I can stop all other duties but not forgetting my sons' medication because that is what holds their life.

There are things that I feel like doing, such as going out there to look for things that I can buy and sell but the other part of my heart thinks that so what if I go and spent days like what I see other women doing. I don't know, maybe I may go and my son will get ill while I am away.

What makes me happy is everything, just being his mother, just seeing them growing and being identified as the mother of these two I just feel excited.

I think there are some women who do not have that kind of privilege of being a mother and some do not have a child even a sick child, some do wish to have one, so I really appreciate what I have.

I play with them with different things, like when we are at home and I have time, I sit and play with them. He enjoys playing Amhina (a traditional game) that is what he can hear. I also play with him using a ball and there is also some drums which we were told to make for them at CRU, so that is what I can play for him while beating the drum, while he nodes his head showing that he is enjoying it.

I find it difficult when it comes to time to visit the clinic especially when dates clashes or even when dates are not clashing preparing to go to the clinic and you are rushing to bit the queue. It really needs wise time management. The time is too little that you leave the house without eating.

Like church functions, at times we do church baby welcomes and you want to attend without the children, so I can't attend such functions. At times I would want to go and join others who are doing Decorations at church; you can't because of the children!

I am taught how to pray alone, to be able to pray for all my situations even when my child gets ill I can pray for him. Having a relationship with God, it comforts. Also a church relative and a blood relative are different because a church relative understands better, even if you ask for something to go and cook for the children, she gives rather if you ask your neighbours they will go and talk about you. Even when I don't have bus fare my pastor does assist further.

Participant: Kudzi

You will just accept it.

There was a time when my child got ill and was admitted at Harare Hospital. We were told that we would be tested. I was the one who was tested because they say if they find out that the mother is negative then there would be no need to test the child. So I was tested and was found negative. We stayed in the hospital for at least two months and child's health kept on deteriorating. One day doctor came and tested the child. That is when the child was found to be HIV-positive. And one of the nursing sisters (who was of old age) came to me and said 'when his father comes, tell him I want to see him' and when the father came, he went in to see the sister. The sister talked to him and eventually convinced him to be tested and he was tested. He was found to be positive.

Haa there was a time I was so worried.

Yes, that is one other issue that torments me, because you would say to yourself; She is growing up she will reach a stage that she will know that she is positive and now....she wants to know how it happened....How will I tell her?

Haa no! where ever I am , thus were my child will be, I cannot leave my child with anyone else....(nodding her head sideways) no one will be able to take care of the child.

What excites me is that at least I have a child; there are some people who do not even have any.

At the present moment, with my relatives no relative of mine knows the situation; I haven't told any especially if it is my own relatives from my side. I avoid telling them because I had a sister who was diagnosed HIV-positive, they would talk a lot of stuff about her. For example at funerals gatherings, they would say a lot of stuff about her, stigmatising her. They would say a lot of stuff that even affected me. You know, you would hear someone saying "aka kanorwara neAids katora here mushonga yeHIV" (has this AIDS patient taken her HIV medication) ...so you just see avoiding such people is the best. Maybe I was going to tell them if I was the one diagnosed with HIV, not to tell them that my child is no, no, no I can't.

I am not afraid of them asking me to divorce my husband, but it is about my child, they will stigmatise her and she will be unhappy, even if she goes on holiday at her granny's place, they would avoid my child playing with other kids.

I used to go to South Africa to buy some stuff but it's no longer possible, because I cannot leave my child with anyone else, who cannot monitor her medication because she has to get her medication on time so you need to be home.

Haa funerals where I have to sleep over, I no longer attend. At present I don't want to lie, I have not gone, I may just go if its near, I go in the morning spend the day there up to around 6 pm, I go back home knowing that I have to give my child her medication in time, at 7 pm sharp.

I mean maybe if you give someone to take care of him, you are giving that person a big task to do because he has to take her pills often, also the type of food he should eat is different from others, so it means you just have to take care of your own child.

The other thing is we have learnt what HIV/AIDS is all about, some people still has the stigmatisation, and they would think that it will spread by just taking care of a child who is positive.

Yes, for instance you have given your mother the child to take care and she is in the rural areas and it's time to plough the fields. Her fields are a distance away and she has to go to the fields at 5 am, and my child should be given tablets at 7 am, how can she balance the two

It's not difficult for me because he is my child and I sacrifice because that is what (Ndozvazviri) is there.

Even up to now I haven't told my mother about my condition even when I visit my sisters place I just lock myself in the spare room and give my child his medication or use the toilet room so that people won't see me. I will just be avoiding being stigmatised.

The church and the location (suburb) is just the same thing. Like at church it depends if the Pastors wife can keep a secret because you can tell her and she discloses to the people.

I think you have noticed a difference with my child comparing to those days, so you would realise that it is just difficult to give my child to somebody else so it's better to take the responsibility myself monitoring his condition.

Definitely you do all the time, even if he cries just thinking of the pain you will be going through to take care of him.

There are for instance my wish was to be able to go and order stuff to sell but now I can't and the journey is long. I can't go with him and leaving him behind with his condition with someone else is not an option.

The important task is food because the pills that he takes needs food because he needs to eat every hour so you are ever on the stove.

Yes, I do like going for parties to relief stress.

It is just exciting to take care of a child and knowing that he is your own child. It is also very comforting. If you just think that there are others who do not have kids, I do feel happy even if he is positive I don't mind that.

The challenges that I normally face is maybe travelling with him, food wise as he is a person who eats often. So when travelling it means carrying a lot of food with you.

Participant: Zivai

You see what happens some people did not accept his condition so it's difficult for such people to take care of him, or even plan anything for him, so you see yourself as the only person who is able to take the responsibility.

Like when you have told them his condition, so you now see how they play with him, and when he gets sick they do not take it seriously that he is ill, they don't value it.

Some are shy and some have seen others disclosing and then not being accepted in society or you would prefer keeping it to yourself.

So during the upkeep of the child are there any other things that you feel nobody else can do but only yourself.

As for me, there is nothing I can say no other person can do for my child, what I can say is that I do not give to anyone his medication, thus the only thing I only give to certain individuals whom I trust. I normally leave him with my sister and she knows and she is used to it and I know he is very safe. At times I live him with his father like yesterday I left him with his father. He is very much supportive.

From my own point of view I would say I attend a lot of workshops so I view myself as more knowledgeable of taking care of him than anybody else, if it's somebody else he would treat him the same way he would treat other children.

What I have realised is his food that what he is supposed to eat should be taken on time which differs from other children who do not have a strict timetable because they do not take pills. But with him his pills follow a timetable and it's after meals.

At the moment, I just wish to get something to do that will sustain me, although I am not employed anywhere, even if I get something to sell like what I am doing now, selling meat, but what I was thinking of if I get cash was to become a cross border, it would be better as I used to be one but could not continue because of the condition of my child.

What excites me most is that he is not different from any other children even when you put him amongst other kids, you won't notice the difference but I do because I know his condition. My child looks fine and more than fine than other normal kids and that really excites me.

The most difficult part for me is that my child cannot walk so it is difficult for me to leave him with anyone else while that person has to do other things apart from taking care of the baby. Also even with him, at times he wants to follow others(children) but he can't and he needs someone to hold his hand so he can walk and at times no one is there to do that for him.

Taking care of a child with a disability needs someone with a good heart and who has patience. because at times when you are doing something and he wants something so it needs patience to be able to stop what you are doing and attend to him, otherwise you can be harsh to him.

Yes there is, like some when performing some household duties and he is playing on your workstation, and at times he needs your assistance and at times you are just following him checking on how he is doing and that eats in to your time and at the end of the day you don't finish your duties.

As for me, I have accepted it and so at times I do my work when he is asleep. Or I place him on my back so that I do whatever I want to do on that day.

I can say I prefer him to be near me always than the other brother because the brother can do everything for himself as compared to him he needs my assistance.

I don't differentiate them much, I try to be fair although the elder one knows that he is older than him, he knows he understands it.

I can say like at present he is able to select things that he like even on TV, he can suggest what to see, or clothes he is able to choose what to wear.

At times it is depending with the situation you are in but at times it is not. At times when you are ill yourself that is when it is very difficult because he won't have anyone to assist him.

I just try to accept it and knowing what I am supposed to do to avoid such situations.

It is difficult because at times your child want to go and play outside and you are avoiding taking him outside and only wanting to take him out when you are there. So if I am inside then I have to force him to stay indoors. It's difficult because child wants to play outside but he can't because I still have to be in the house.

My wish at the moment is for my son to be able to walk and also to people in the society to be able to accept other people's situations.

When I was pregnant, I went to the clinic and I got tested when I was 3 months pregnant and I received my results stating that I was HIV-positive, that same day I was given a pill, which I was told that I should take the day I will start having labour pains, they also said that I should collect the other set of pills when I am 7 months pregnant. I went back at 7 months and I asked for the pills and I was told that the people who distribute the pills were not around, I waited until the day passed and I went home. I came back for the next month's review when I was 8 months old, thinking that I would get the tablets as I was told that I would be given. Unfortunately I could not get the pills until I finally gave birth to my child. When my child was 6 months old, he had oral thrush, so I took him to the clinic and he got medication, thus when my child was tested and was diagnosed to be HIV-positive, I went with him for CD4 count and it was low and he was started on ARVs so he started on this program when he was 6 months.

But I can safely say that ever since he started taking pills I don't have any problems but since he started taking pills, I don't have any problems but since from way back, he was ever sick but now it has changed.

At first before I meet others, with such problems, it was difficult for me to accept it, but when I saw others, I realised that my problems are far much better than problems of others especially here at CRU.

In the first days, it used to worry me a lot, (tears starting to come out). But now I am better. I am getting used to it, with time I will be fine. I would feel a lot of pain crying. I would look at him and say 'it's not his fault'. He did nothing wrong but we did it... as parents.

What should I say, Should I say I did it...I can't!

What makes me happy is that he is a human being like any other person. It's only that he cannot walk nor do other things, but his mind is fine, he reasons like any other human being.

If he is playing outside and we are just the two of us at home, mostly we spend the day just the two of us, If there is a visitor or someone who wants to buy something, he comes crawling or walking with support of walls and tells me 'Mama diwa' you are wanted. (With a smile), yes I depend on him. I sell some stuff, he knows that we sell. When playing he can just come from wherever he would be playing and start knocking on the door, saying 'dakutenga' I want to buy, so you see that he knows.

Normally, I can go where he is playing, I sit with him, if he is playing house, he would ask 'Mum do you want sadza?' I reply 'Yes', we sit in such a way that we can share the sadza he would have cooked with mud. I also play during the time I would be doing exercises with him.

You love them all but with his condition you tend to love him more than the other one and you try not to be selective but inside your heart you know where your heart is.

No there is no much difference. The difference is that the older one could go for holidays even when I would travel I would safely live him with anybody and even when he was of his age I was working so I would live him in the hands of the grandmother but with him he has never stayed at her grandmother's place.

I can say it's hard in the sense that you can't get someone whom you can trust to take care of your child because he has a timetable of taking pills and for taking his food. I just feel that he cannot go for long without taking his food and also his time for taking his pills. It can be difficult for one to put him on her back since he is big. It's difficult for someone to accept it.

So far I can say what I am doing is the selling of meat (beef and chicken cuts). The profits are low and I cannot make big orders because of the condition of the child. I may be called to the clinic, or he most of the profit is spend on the needs of the child. Also I am not doing the cross boarder thing because funds are not permitting.

It is difficult because I have no one to leave the child with; who can I leave him with.

I would also suggest that the health people should distribute the pills earlier, like in my position what worries me a lot is that I went early to register my pregnancy but up to the time I gave birth I was not given pills. I could have not passed the virus to my child.

Like the time I was given the first pill, they could have given me all of them and the virus could not have spread to the child.

Some man ran away from home, the moment they find out for me it's much better because we are together.